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Final Payments

Socio-economic Costs of Palliative Home Caregiving in the Last Month of Life

2002

Project Team

British Columbia Centre of Excellence for Women's Health: Lorraine Greaves, Olena Hankivsky, Georgia Livadiotakis, Renée Cormier, Lyndsey Saunders and Lindsey Galvin

Centre d'Excellence pour la sante des femmes: Bilkis Vissandjee, Patricia Carlier and Margareth Zanchetta

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Executive Summary

This study assesses the socio-economic costs and benefits for both female and male informal and formal caregivers¹ providing palliative home care (focusing on the last month of life) to a cancer or AIDS patient. Eighty-one caregivers, with equal representation of male and female informal and formal caregivers from the provinces of British Columbia, Quebec and Nova Scotia, were interviewed about their experiences giving palliative home care to a friend/family member or a client. The data were analyzed to determine gender differences, differences between formal and informal caregivers, and regional and diagnosis-related differences.

Home (and community) care refers to a range of services that assist people with a variety of conditions in being cared for outside of institutions. This report situates palliative care within the context of home care and describes the evolution of palliative care policies, programs and services, paying particular attention to the provinces of British Columbia, Quebec and Nova Scotia.

This research examines a comprehensive set of costs and benefits – including social, economic, emotional, psychological and spiritual – experienced by these caregivers. In so doing, it fills a knowledge gap pertaining to the experiences of palliative home caregivers who care for someone who is in the last four weeks of life. The data suggest that during this time home caregivers report a wide range of impacts in all categories.

The economic impacts range from out-of-pocket expenses to lost hours at work to job interruptions. Physical impacts result from taking on a wide range of tasks from dressing and feeding patients to providing recreation and social experiences for them. Socially, the caregivers report that they access a wide range of different community supports to assist them, with varying degrees of satisfaction. In terms of spiritual and psychological impacts, the caregivers report both positive and negative aspects, ranging from getting meaning from the experience to becoming emotionally exhausted by the task.

This study uncovered significant differences between the experiences of formal and informal caregivers who provide palliative home care. Informal caregivers spent much more time on caregiving tasks and were more likely to report a physical impact. In addition, the informal caregivers incurred more out-of-pocket expenses than the formal caregivers and performed approximately \$6,000 worth of caregiving labour in the final four weeks of a patient's life.

The tasks undertaken and services requested by caregivers reveal a somewhat gendered pattern. Female and male caregivers (both formal and informal) differed in the nature of tasks undertaken and social services requested to support caregiving efforts. Females were more likely to dress their patient and obtain services such as massage, while males were more likely to assist with financial and legal affairs and to

¹ Throughout this report, informal caregivers, unpaid and family/friends caregivers are used interchangeably. Similarly the terms, formal, paid and community-based caregivers are also used interchangeably.

obtain individual counselling services for their patients. Among informal caregivers, females were more likely to be dissatisfied with the quality of their own caregiving efforts than males, and for those caring for a cancer patient, more likely to report that caregiving affected their family life. Informal female caregivers were more likely than both formal and informal male caregivers to report a physical impact as a result of their caregiving efforts.

As would be expected, different diagnoses indicated different kinds of caregiving teams. Caring for AIDS patients usually involved friends as informal caregivers, while cancer patients usually had family members or spouses as carers. Caregivers of AIDS patients were more likely to purchase specific items to assist in the caregiving, and more often reported economic hardship in their patient's family as a result of the caregiving effort. Cancer caregivers were more likely to request additional, skilled nursing services than AIDS caregivers.

Finally, several regional differences emerged in this study. Caregivers in different provinces utilized different resources, perhaps reflecting local policies, practices and geography. For example, B.C. caregivers incurred the most out-of-pocket expenses and travelled the greatest distances to provide care, but were less likely to utilize transport for their patients. Nova Scotia caregivers were more likely to obtain respite care for their patient. Overall impact was reported differently as well. For example, Nova Scotia and B.C. caregivers were more likely than Quebec caregivers to report an emotional impact on their life as a result of the caregiving role.

This study represents an initial examination of a range of socio-economic costs and impacts on palliative home caregivers, both informal and formal. It reveals that palliative home caregiving has an enormous impact in a variety of ways on both types of caregivers, with informal caregivers reporting significant economic costs to providing care in the last four weeks of a patient's life. The tasks performed by male and female caregivers were somewhat different, with the female informal caregivers being considerably more self critical when reflecting on the job they had performed as caregivers.

Most of the caregivers reported significant benefits and positive aspects to the caregiving experience. Only a small minority reported a negative impact on the quality of their relationship with the patient, while the vast majority reported that their relationship with the patient had improved as a result of providing palliative care. Specifically, and importantly, the majority of the caregivers reported that their caregiving efforts were acknowledged by the patient, and that the overall experience of providing palliative care gave increased meaning to their lives.

I. Introduction

A. Home Care and Palliative Care

Home care and palliative care, previously considered subsidiary areas of health, are emerging as primary fields in their own right. **Home care**, also known as community care, enables individuals of all ages to receive a range of medical and social services in the comfort of their home environment. Home care in Canada has three main goals. The first is to provide care that would otherwise be provided by hospitals and long-term care facilities. The second is to provide a health care setting that maintains clients in their home environment thereby providing cost savings to the system. Finally, home care is intended to prevent further deterioration by providing support and monitoring services to help outweigh costs in the long term (Health Canada, 1999). These can be summarized as follows:

- Substitution (for services also provided in hospitals and long-term care facilities)
- Prevention (providing services and monitoring, which, over time, lead to overall lower costs of care)
- Maintenance (allowing clients to stay independent in their current living environment)

Palliative care has become a significant, albeit distinct and specialized component of provincial/territorial home and continuing care programs. Although definitions of palliative care vary, the following definition of the Canadian Palliative Care Association is instructive:

Palliative care is aimed at the relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved. It affirms life and regards dying as a normal process. It neither hastens nor postpones death. It provides relief from pain and other distressing symptoms. It integrates the psychological and spiritual aspects of patient care. It offers a support system to help patients live as actively as possible until death. It offers a support system to help the family cope during the patient's illness and their own bereavement. (Canadian Palliative Care Association)

This definition affirms that dying is a "normal process" and as such, health care professionals should integrate the psychological and spiritual aspects of patient care in order to support terminal patients who need relief from pain. In addition to patient care, palliative care affirms that services should be in place to support the families through bereavement or other counselling services (Johnson & Abraham, 1995).

While there is some inconsistency in the palliative care literature as to when the care process becomes palliative, according to health care professionals, palliative care usually begins when the disease becomes terminal, which generally means a three- to six-month life expectancy (Dudgeon et al., 1995). There have been pressures exerted to change the meaning of palliative care to include treatment "throughout the course of the illness and not merely during the terminal phase" (Dudgeon et al., 1995: 5). Similarly, Boyd (1993) reveals that there has been a movement towards delivering

palliative care based on need and not merely on life expectancy. To date, however, such shifts have not been made.

The functions of palliative care therefore remain particularly unique. Unlike many other kinds of home care, palliative care is time limited and narrowly focused. It is specifically intended to improve the quality of life of terminally ill patients and their families by providing symptom management, pain relief, psychological care and bereavement support.

Models of health care delivery in both home care and palliative care have often evolved faster than the processes to measure and monitor them. It is this relative newness, in combination with the breadth of services and activities that fall under these categories that make our understanding of home-based palliative caregiving limited at present. We do not have a nationally accepted set of standards or measures to assess the experiences and outcomes for the patient or the caregiver, and lack knowledge of some of the broader issues that affect both caregivers and patients involved in palliative home caregiving. The need for such standardization in the delivery of home-based palliative care may acquire greater urgency, as the health system's focus shifts away from acute and facilities-based care.

There is a great deal of variance across regions in Canada with respect to the availability, delivery and administration of home care services in general. There are no common sets of tasks that home support workers perform, nor is there a common job title. Vague distinctions between part-time, full-time, informal, formal and skilled professional workers have created measurement and enumeration obstacles. Furthermore, little is known about the impact of home care services on health, lifestyle and economic outcomes or the extent to which the burden of care has shifted from institutions to patients, families and community agencies. Finally, a significant discrepancy exists in training levels of home care workers. Whereas licensing and regulatory bodies ensure that professional workers adhere to recognized standards, there are no standard training requirements for informal caregivers.

B. Palliative Care Programs and Services in Canada – An Historical Overview

The palliative movement in Canada dates back to 1948, when a number of federal research grants were established to improve the delivery of health services for terminal patients (National Health and Welfare, 1982). Until 1989, palliative care was offered in various institutional settings including nursing homes and hospitals. Unlike the U.S. whose palliative care service delivery model emphasized the home or community environment (Renzendes & Abbott, 1979), the Canadian movement sought to utilize the existing institutional infrastructure as a means to meet the growing number of patients requiring terminal care.

Following the establishment of national guidelines outlining the delivery of services in hospitals in 1950, palliative care units opened across the country (Health Canada, 1998). Although it was a Montreal program that first introduced the possibility of coordinating palliative care services to terminal clients in their home, these services were not deemed nor termed "palliative care"; rather, they were incorporated into the existing care practices among professional home support workers (National Health and Welfare, 1982). With the establishment of the Canadian Palliative Care

Association in 1980, rapid improvements towards the care of the dying were made, particularly with the possibility of home deaths. In 1989, the association revised the federal guidelines on palliative care services to integrate palliative treatment within provincial home care programs (Health Canada, 1997). By 1990, all provinces and territories except for Nova Scotia had established and/or incorporated palliative care into home support services. In the early 90s, task force groups were established to advise the federal government on how to improve the care of the terminally ill (Health Canada, 1997).

The shift to community care was reinforced by the Special Senate Committee on Euthanasia and Assisted Suicide, who recommended that each province give "sufficient place for palliative care in the community" (Health Canada, 1997). With the creation in the 1995 of *Towards a Consensus in Standardized Principles of Practice*, the Canadian Palliative Care Association set the policy structure to assist provincial and regional governments in the development of a palliative care strategy (Health Canada, 1997). With the more recent symposium on Palliative Care in Ottawa in March 1997, provincial and territorial palliative care experts recommended that Health and Welfare Canada adopt a national approach to palliative services at home to build collaboration for future development (Health Canada, 1997).

In 1999, Health Minister Allan Rock announced that the Honourable Senator Sharon Carstairs would be responsible for palliative care in Canada. As part of this mandate, a special senate sub-committee was established to examine end-of-life care in Canada. In June 2000, this sub-committee produced a report entitled *Quality of End-of-Life Care: The Right of Every Canadian*. In this report, members identified that service delivery should include:

- Accessibility to services (institutional or community)
- Provision of services by interdisciplinary teams
- Availability of services when needed (few hours or 24-hour care)
- Availability of service before death is imminent
- Broad range of services responsive to client cultural diversity and illness
- Education in pain and symptom control management
- Support for formal and informal caregivers

One year later, in June 2001, Senator Sharon Carstairs together with (then) Health Minister Allan Rock announced \$1 million in funding to co-ordinate the development of a national strategy called, *End-of-Life Care: The Right of Every Canadian*. This national strategy is being co-ordinated by the Quality End-of-Care Coalition together with the Canadian Palliative Care Association. In November 2001, the commitment to palliative care grew with a funding announcement for a virtual Canadian hospice.

At present, there is no national policy governing palliative home care. Rather, the strategy being pursued is to include palliative care as an integrated component of the existing home care programs in the provinces and territories. Palliative care is therefore part of the continuum of care offered by the existing community health systems created in each province.

C. The Rationale Behind Palliative Care

The movement of palliative care services to the home can be attributed to a number of developments. Population aging, increased life expectancy, technological advancements at home, increased incidence of cancer and AIDS, and the quality of terminal care together support the need to restructure palliative services so that they are offered to those wishing to be cared for in their home (Timery et al., 1994). Abyad (1993) argues that the success of palliative care in the home care system is attributed to the dissatisfaction of patients and health care providers with the management of terminal illness in the traditional acute and curative system.

Organizationally, there has been a progressive movement away from the original medical care model that is practiced in hospital settings towards a more multidisciplinary approach that emphasizes the holistic needs of patients and facilitates the interconnection between hospital and community-based services. Field and James (1993) argue that the shift towards community care has meant that hospitals are increasingly becoming places where acute, intense, short-stay treatment is given; whereas, the community, including residential and nursing homes, is now the preferred place for long-term care. According to an Angus Reid report, 84% of all Canadians surveyed indicated a preference to spend their final days at home with their family (Dudley, 1999). Reflecting similar trends, Kelly, Chu and Buehler (1993) argued that the number of hospital deaths in the U.S. would decline significantly among AIDS patients.

It is important to consider ways of measuring relative costs of home or hospital palliative care when considering allocation of health care resources. However, making cost comparisons is difficult, as the home environment cannot be measured the same way as the hospital and vice-versa. The literature remains inconclusive about which environment is more costly to care for the terminally ill. What is clear is that the last months of life are the most costly for both the health care system and for individuals and their families (Abyad, 1993; Sheppard et al., 1996).

Some studies found that hospital care is cheaper (Brooks, 1989), while a growing number of studies find home care is less costly (Maltoni et al., 1998; Lane et al., 1998; Birnbaum & Kidder, 1984). Despite these research findings, Bailes (1995) and Gomas (1993) argue that the debate remains mixed, as studies need to examine the type of care or services rendered. The literature has failed to acknowledge individual variations, where measuring cost is susceptible to homogeneity when in fact the terminal population's needs and demands from palliative care services are very much heterogeneous. However, Gomas argues, "for an equivalent patient, and equivalent treatment, care will always be less expensive at home as the personal infrastructure and family support is already there" (1993:47).

Prigerson (1991) suggests that terminally ill patients, especially those over the ages of 65, have been found to prefer the care offered through home hospice as compared to the life-sustaining techniques received in the hospital. Nevertheless, Prigerson notes that despite these preferences, proportionately fewer elderly patients are able remain in their home and receive home supports. As a proportion, higher percentages of seniors with a terminal illness are dying in hospital or other institutional settings. Scott (1992) argued that by the year 2000, 60 to 70 percent of the terminally ill in

Canada would be dying in institutions. These numbers compare to the over 80% of the terminally ill in the U.S. who die in institutions (Vachon, 1998), and 75% in the United Kingdom (Boyd, 1993). The greater number of studies have found that home deaths are becoming increasingly rare (Lane et al., 1998; Karlsen & Addington-Hall, 1998), particularly for persons with AIDS (cited in Dugeault et al., 1999).

When is a home death possible?

Home deaths are largely dependent upon the characteristics of the patient and their family (Hinton, 1994a). Research has identified that those who are more likely to experience a home death have a higher socio-economic status as they have more resources needed to purchase the home supplies and services required for 24-hour care (Vachon, 1998; Grande et al., 1998; Daneault et al., 1999; Smith, 1994). These patients also do not live alone and have a primary family caregiver who is healthy and willing to provide the care needed (Grande et al., 1998; Gomas, 1993). Studies have also found that a home death is experienced when the patient has accepted that their illness is terminal (Vachon, 1998; Grande et al., 1998; Hinton, 1994b; Prigerson, 1991).

Although few studies have applied a gender analysis to home deaths, Grande et al. (1998) found that older males who are cared for by their wife are more likely to die at home as compared to older women. Unfortunately, research remains inconclusive as to whether age plays any role in experiencing a home death. Some studies found that younger populations are better able to accomplish a home death (Neale as cited in Clark, 1993), while other studies contradict this finding (Vachon, 1998; Prigerson, 1991).

Research has also found that palliative home care offers many added psychological benefits to the terminally ill patient as the physical environment enhances independence and quality of life (Kinsella et al., 1998; Lubin, 1992; Peruselli et al., 1997; Abyad, 1993). While measuring the quality of life of the terminally ill in their home, studies also measure the ability of the home support team to control the symptoms and manage pain (Ferrel, 1998). Although, the inability to manage pain at home is one of the leading factors resulting in patient hospitalization (Ferrel, 1998; Brown et al., 1990; Hinton 1994a; Field & James, 1993), a number of studies have found that pain control was possible for the majority of clients at home (Mercandante et al., 1992; Peruselli et al., 1997).

When is a home death not possible?

A home death becomes impossible for patients who do not have a primary family caregiver or are not supported by their family (Gomas, 1993; Vachon, 1998). Johnson (1995) argues that "our understanding of the concept of 'family', a priority unit of care in the context of palliative care, has expanded after years of caring for gay women and men" (p. 42). With an increase in AIDS cases, familial support is challenging home care policies that foster the participation of lay or family caregiving (Tirmey et al., 1994). Other researchers have also identified that home deaths clearly become impossible when the patient does not have a home to go to (Stajduher & Davies, 1998). Johnson (1995) argues that palliative home services become extremely challenged by situations such as patients whose homes are single room hotels where no telephone or bathroom is available, and the patients prefer to remain there.

Thus, the issues for those who are unable to die at home are beyond those typically raised in the literature, even though they are fundamental to the discussion. Limited community, social and familial resources will also contribute to a patient's move to an institutional setting. Stajduher and Davies (1998) argue that there are insufficient community care resources available and that home care services are too few to support the 24-hour care that is required for terminal patients wishing to die at home (Stajduher & Davies, 1998). As a result, the informal network is left supplementing this care.

D. Health Reform and Palliative Home Caregiving

Clearly, all of these factors and influences are affected in an era of health reform such as that which Canada is currently experiencing. As many resource-related pressures are being applied to governments across the country with respect to health care, suggestions continue to flow regarding the appropriate restructuring of home and community care systems, including palliative care. Several organizations and bodies have suggested reforms to ensure a consistent home care system based on national standards that protects both patients and caregivers.

For example, the Canadian Association of Retired Persons (CARP), which lobbies the government on behalf of Canadians over the age of fifty, has produced two reports on home care. The 1999 Report on Home Care: Putting a Face on Home Care identified the variation of services within provinces, between provinces, and between rural and urban areas (CARP, 1999). CARP's 2001 Report Card on Home Care in Canada: Home Care by Default, Not by Design grades specific aspects of Canadian home care, including strategic direction, funding, human resources, service delivery, informal caregivers, data, and knowledge about home care. The report also focused on grading policy at the provincial/territorial level. Ultimately, the report suggests that the federal and provincial/territorial governments must develop sustainable funding to support a home care program that meets both acute and chronic needs, that integrates national standards, uniformity, and guidelines as well as a common national definition for home care (CARP, 2001). The CARP report successfully addresses issues such as disparities of caregiver training with a depth that other reports tend to lack or ignore altogether.

Specific to palliative care, the Canadian Palliative Care Association (CPCA) advocates on behalf of Canadians for the development of national procedures in hospice palliative care. Since 1993, the Standards Committee in the CPCA has initiated the development of national norms of practice for hospice palliative care, in consultation with Canadians who participated in their surveys. The purpose of these norms is to provide hospice palliative care programs and services with consistent and comparable responses to relieve suffering and improve quality of life for patients and their families. The CPCA published the proposed nationally accepted norms of practice in 2001 (Ferris et al, 2001) and a model based on these national principles and norms in 2002 (Ferris et al, 2002).

While focussed on hospice care, the CPCA offers a model that is comprehensive and useful for future policy building. The patient and their family constitute the core of the CPCA framework. Furthermore, unlike the other models, the fixed characteristics of the patient and family (such as age, gender, ethnicity, race education and literacy)

are highlighted. In acknowledging these traits as factors that potentially affect quality of care, the CPCA model is a significant contribution to the field.

Clearly, future health care reform will affect the delivery of palliative care in Canada, in home and in institutions. Similar to other areas of health care, the focus is on the issue of ensuring quality, and developing methods of measuring quality and effect, evaluating programs and maintaining standards. Much of this work pivots around the notion of developing indicators of quality, to measure both the health of patients as well as the effect of programs of care.

Palliative home caregiving is an area where quality indicators and improved measurement are required. Increased accountability, protection of patients and caregivers and establishing and ensuring standards of care are all key components of the drive for more study of palliative home caregiving practices. An element of key concern to the caregiver and the patient is the issue of costs and their distribution when and if palliative caregiving locates in the home context. While palliative home care may be cost effective for governments, and may be welcomed by patients, the issue of transferred or new costs deriving from this shift is understudied.

In particular, health care costs are often and generally perceived to be solely economic in nature for purposes of public policy debate, while many other "costs" and indeed, some benefits derive from developing models of palliative home care. This study addresses this core issue in order to do a preliminary exploration of the nature and extent of costs and impacts for both male and female formal and informal caregivers offering palliative home care in the final month of life.

II. Key Issues

A. Recognizing the Demands on Informal and Formal Caregivers

Research has shown that caregivers routinely deal with the following range of demands:

- Caregivers are responsible for providing quality care in assisting with various activities of daily living (ADLs), instrumental activities of daily living (IADL) and pain management. Without the proper instruction and training of these tasks or pain management control, particularly oriented to caring for AIDS or cancer patients, the caregiver may experience physical exhaustion.
- Caregivers also respond and manage difficult behaviours that are associated with disability or illness. For caregivers of AIDS patients who continue to use illicit drugs or express aggression, mental hardship may be experienced.
- Caregivers may also become responsible for identifying, coordinating and managing different services and service providers at home. This can create an emotional toll for many caregivers.
- The demands of caregiving may also interrupt, curtail or preclude the caregiver's personal and familial responsibilities.

Caregivers of terminally ill patients are faced with other more specific challenges related to end-of-life care.

In cases where the terminal patient is frail and no longer able to assume the total responsibility for their care, the role of the family as the decision maker is heightened, often resulting in emotional and psychological discomfort (Prigerson, 1991).

The decision when and if to hospitalize is often a key emotional issue. It represents a tension between the family's desire to relieve pain and receive respite and the patient's wish to die at home. Although studies have found that families prefer to care for their terminal family member at home (Brown et al., 1990; Kinsella et al., 1998), many families also favour hospitalization when home care becomes a challenge. For example, Brown (1990) states that when the patient loses his/her mobility or has multiple needs, hospitalization is often preferred. In addition, hospitalization is preferred when the family is unable to manage the patient's pain. Ferrel (1998) found that patients and families hold similar beliefs about pain, but the family caregivers tend to have a higher degree of emotional distress associated with observing pain in their family members.

Palliative caregivers are also quite frequently required to provide spiritual comfort during the preparation for death. From its beginning, hospice and palliative care has included the spiritual element in care (Dudley, Smith & Millison, 1995).

B. Acknowledging the Gendered Nature of Caregiving

It has been estimated that 80 to 90% of the care at home is provided by family caregivers, usually women, on an unpaid basis (Cranswick, 1997; Keating, 1999). Largely due to gender role expectations, studies have shown that women are more likely to perform hands-on, long-term assistance (such as bathing and grooming) while male caregivers provide tasks related to physical labour (such as transfers and transportation), which are more likely to be short term (Joseph and Hallman, 1998; Kaden and McDaniel, 1990).

There is limited knowledge on the gendered nature of home and community care, due to a limited range of studies in the areas that are gender-sensitive in their design. Morris (2001, iii) identified only 184 out of 2,000 studies on home and community care that were gender-sensitive. Within that group, Morris was also able to identify some key research gaps regarding the role of gender in understanding home and community care. According to Morris, some key issues needing research (pertinent to the palliative home caregiving field) include assessing the long-term financial impact on women and men of care-related labour force and income interruptions. In addition, she recommends research on a range of diversity issues connected to understanding the provision of home care and research adding to our understanding of both men and women caregivers.

The greater proportion of caregiving research has been conducted on caregivers of a senior family member with a chronic illness. Very little gendered research in Canada and the U.S. exists that has examined caregiving for palliative or terminally ill clients. Rather, some of the existing body of literature on palliative care uses sex as a significant independent variable yet reports and discusses findings in terms of gender. Most importantly, the majority of the participants in these studies are female, thus there is a failure to report a complete gender-based analysis that can explain and compare how women and men are affected by their caregiver role. With this in mind, there is a need to expand home care research using a gender-based approach.

Despite these limitations of the caregiving literature, there are studies that report that the caregiver role has more of an impact on women. Keating et al. (1999) argues that the impact of caregiving relates to the amount of time spent providing the tasks. In other words, the greater amount of assistance women provide, the greater impact will result. A number of studies have found that women report significantly greater burden than men (Hawranik and Strain, 2000; Keating et al., 1999) and express interference with their personal life and career goals (The Canadian Study of Health and Aging, 1994). In fact, Murphy et al. (1997) found that the overload in daily tasks that female family caregivers had to perform lead many to report feelings of multiple role conflict.

These pressures can explain the finding that caregiving can negatively impact the health of the caregiver. Keating et al. (1999) found that almost two-thirds (27.5%) of females participants compared to 10.6% of male caregivers reported negative health effects resulting from their caregiving role. A 2002 study from Britain found that 21% of women providing care to sick, disabled or elderly family members or friends reported mental health problems, compared to 12% of men, and carers who spent the most time caring had worse mental health (Office for National Statistics, 2002).

Research has also reported that the socio-economic status of the caregiver is an important consideration when evaluating the impact. Cranswick (1997) found that a almost 46% of male caregivers incurred greater out-of-pocket expenses to provide health care assistance compared to their female counterparts (42% for females). This study aims to enhance the literature in palliative home caregiving by investigating some of these issues for both male and female caregivers.

C. Noting Disease-Specific Characteristics of Palliative Care

Any form of caregiving is directly affected by the kind of care that is required. More often than not, the demands on informal and formal caregivers will be determined by the nature of a particular disease or illness, the family, friends, and community supports available, and any other social/cultural factors that affect how a particular disease and affected patient are viewed and responded to. This is particularly true for the two disease groups investigated in our study – cancer and HIV/AIDS.

Cancer

What makes cancer palliative care distinct is that it has been the “prototype” disease for organizing end-of-life care. There are a number of reasons for this. Cancer, compared to other diseases/illnesses, has a relatively predictable disease trajectory in its final stages and the symptoms requiring treatment are quite similar across different forms of cancer (Foley & Gelband, 2001). Most of those receiving palliative care for cancer are the elderly. For approximately half of those dying from cancer, death involves a myriad of symptoms to which caregivers must attend. These include pain, laboured breathing, distress, nausea, confusion and other physical and psychological conditions (Foley & Gelband, 2001; Phillips et al., 2000; Donnelly & Walsh, 1995). Patient concerns around palliative care are typically psychosocial, including issues around prolongation of dying, sense of control, relief of burdens and strengthening of ties (Singer et al., 1999).

Martens and Davies (1990) have found that the family caregivers of cancer patients reported use of formal supports only to answer questions and to provide factual information about medications to control pain and/or treatment-related symptoms. Because they often undertake the majority of the caring work, caregivers of cancer patients often experience a “heavy and mostly unrelieved emotional and financial burden” (Emanuel et al., 2000).

HIV/AIDS

Generalisations drawn from existing literature on caregivers for persons with other diseases cannot always be applied to the caregiving of persons with HIV/AIDS (Folkman, Chesney, Cooke, Boccillari & Collette, 1994). Significant differences exist that distinguish caregiving for AIDS patients from other groups. High stress can be caused by factors including an inability to predict the course of the disease, its troubling physical effects, and insufficient training for the demands of caregiving. Those diagnosed with AIDS often exhibit an unpredictable course battling with other acute and chronic episodes.

With respect to age, the caregivers are younger than their counterparts caring for other groups, and, in Canada, have frequently been homosexual males. They are often the patient’s partners. As a result of the social stigma of AIDS, these caregivers often

have less access to support services and resources, and as Smith (1994) argues, the patient's partners make extraordinary income sacrifices. In addition, unlike many women, socialisation as a caregiver is not experienced by male caregivers of persons with HIV and AIDS. The assumption of this role may also result in the caregiver being forced into unintentionally disclosing his sexual orientation (Hendrick, 2000).

Moreover, in comparison to terminally ill cancer patients, fewer AIDS patients die at home. In their study of 307 AIDS patients living in extreme poverty in downtown Montreal, Daneault et al. (1999) found that low-income patients were more likely to complain of uncontrolled pain during their final week at home and thus were more likely to die in hospital compared to their financially secure counterparts.

III. Overview of Study

A. Purpose

The purpose of this study was to examine, both qualitatively and quantitatively, the gendered social, physical, economic, emotional/psychological and spiritual costs and benefits that were incurred by informal and formal caregivers during their last month of providing palliative care to persons diagnosed with cancer and AIDS in the provinces of British Columbia, Quebec and Nova Scotia.

B. Rationale

To date, there has been no Canadian study that has calculated the gendered socio-economic costs and benefits of informal and formal caregiving for a terminally ill client, as was the purpose of this study. Rather, in their study *Conceptualizing and Operationalizing the Costs of Informal Elder Care*, Fast and her colleagues (1997) provide a conceptual framework for calculating such costs for caring for persons with acute or chronic functional limitation.

The choice of disease groups – Cancer and AIDS:

Both research in Canada and the U.S. has found that as a disease group, cancer is the leading causes of death and is the most likely disease groups to die at home (Vachon, 1998). In 2001, an estimated 65,300 deaths in Canada resulted from cancer (National Cancer Institute of Canada, 2001). Although lung cancer remains the leading cause of cancer deaths among both women and men, the most frequently diagnosed cancers for women will be breast cancer and prostate cancer for men (National Cancer Institute of Canada, 2001). In comparison to cancer patients who are more likely to be elderly, persons with AIDS are younger (ranging from 25-44 year) with an unknown disease trajectory (Cherin et al., 1998). In Canada, women represent 24% of all HIV infected persons (Canadian AIDS Society, 2000), almost 20% of all diagnosed AIDS cases in the U.S. and more than 50% world wide (Advocacy for People Living with HIV/AIDS, 1998).

The choice of provinces:

This study involved an in-depth examination of palliative home care and caregiving in three provinces (B.C., Quebec and Nova Scotia) as a means to provide a partial cross-Canada comparison of palliative home care. Both similarities and difference between the provinces were identified. The most significant difference is that, unlike Quebec and B.C., palliative care in Nova Scotia is not recognized by the government as a core service at home. As such, terminal clients receive chronic care services to meet their needs from local home care programs. Most District Health Councils (DHCs) have developed their own palliative care programs in accordance to the demands in their community.

In contrast, in February 2001, the B.C. Government introduced the Palliative Care Benefits Program where the costs of pharmaceuticals, medical supplies and medical equipment required in the home would be provided at no charge to the patient and/or their family.

A further distinction between these provinces was found in their data collection systems. While B.C. has a Continuing Care Database that collects a range of statistics on palliative care services and the number of clients across the province, both Nova Scotia and Quebec do not. As a result, it becomes a challenging task to identify the total number of clients receiving care at home.

C. Study Context – Provincial Palliative Home Care

1. British Columbia

On February 1, 2001, with the introduction of the Palliative Care Benefits Program, palliative care service delivery in the province underwent a substantial change. The program allows patients who wish to live out their final days at home coverage for the cost of eligible prescription and non-prescription medication, and medical supplies and equipment that would have otherwise been offered in an institutional care setting.

Prior to this date, palliative care services were delivered at home through existing regional Continuing Care Programs. Since 1978, the Continuing Care system has co-ordinated service delivery to eligible clients in their home but was enacted into legislation in 1980 with the *Continuing Care Act*. Continuing Care consists of the Long-Term Care, Home Nursing and Community Rehabilitation Programs. Together, these programs integrate the social and medical health services for all eligible clients. In 2002, the BC government streamlined the number of Regional Health Authorities, who are responsible for health planning, policy development and service delivery, from 52 Regional Health Authorities (11 Regional Health Boards, 34 Community Health Councils, 7 Community Health Service Societies) to five Regional Health Authorities and one provincial authority.

In April 1994, the Ministry of Health established a Closer to Home Fund to support regional palliative home care, and developed a joint protocol for the management of planned home deaths. Although the province had a Pharmacare Program in place, only persons aged 65 years or older were eligible to have their medications reimbursed, leaving many palliative care patients, particularly those diagnosed as HIV positive/AIDS, without medication assistance.

Assessment into the B.C. Palliative Care Benefits Program is determined using the Palliative Performance Scale developed by the Ministry of Health. This scale, which is primarily functionally based, rates the patient's performance on various activities and instrumental activities of daily living of a scale of 100; eligibility for admission requires the patient to score of 50% or less. The score cut-off of 50% portrays a functionally dependent individual with personal care tasks, despite their mental capacities. Additional eligibility requirements include: B.C. residence, Medical Services Plan coverage, and a diagnosis of a life-threatening disease or illness with life expectancy of no more than six months.

The number of palliative care clients receiving services at home has increased throughout the years (see Table 1). This may be reflective of new policies that acknowledge the importance of offering alternative service delivery environments for the growing number of terminally ill patients who wish to die in the comfort of their own home. As shown in the table below, between 1992/93 to 1999/2000, the number of palliative care clients in B.C. has grown by 78.8%. The greatest percentage increase has occurred among the female population. At the same time, the percentage of females represented by the total clients each year has remained relatively the same.

Table 1
Number and Percent of Palliative Care Clients in British Columbia by Sex and Fiscal Years 1992/1993 to 1999/2000

Sex	Client Counts								% change
	1992/93	1993/94	1994/95	1995/96	1996/97	1997/98	1998/99	1999/00	
Female	415 46.9%	1590 47.6%	1715 47.8%	1871 48.4%	1858 49.1%	1984 49.0%	1996 49.1%	2073 48.3%	80.0+
Male	469 53.1%	1750 52.4%	1871 52.2%	1996 51.6%	2018 52.1%	2066 51.0%	2073 50.9%	2216 51.7%	78.8+
Total	884	3340	3586	3867	3876	4050	4069	4289	79.4+

Source: Continuing Care Data Warehouse as of March 20, 2001. B.C. Ministry of Health.
+ signifies a percentage increase in clients over the fiscal years

Table Notes:

1. Palliative care is a component of direct care services. Direct care cases are not reported until they are closed. Direct care cases that span multiple years are therefore under-reported while still active and only counted in the year that they are finally closed.
2. The number of clients at the B.C. level is not an aggregate of the regional client counts. A client may have received service in more than one health authority during the fiscal year. The number of clients at the B.C. level is a count of unique clients among all the health authorities.
3. All the clients who received Palliative services in the fiscal year 1999/2000, received these services through Direct Care, Home Nursing Care Program.

2. Quebec

In 1970, the Quebec Government enacted the *Act Respecting Health and Social Services* which governs the delivery of health services at home through Local Community Service Centres (CLSCs) (section 80). The province provides funding to the 146 CLSC's for the delivery of palliative care services at home where each CLSC decides upon their own delivery mechanisms. CLSCs are the primary care provider as services are not contracted out to community health providers. Although clients are billed for service according to a sliding scale (i.e. based on client's income), there is no cost for service to palliative care clients. A 24-hour information health line is also available and enables palliative care clients to by-pass the calling wait list when making a query. Another distinctive feature of CLSCs is that regardless of the client's income, medical equipment for the home is loaned free of charge. Referrals to palliative care services are open. However, services are delivered only when the client has been diagnosed at the end-of-life stage.

Palliative care services, whether delivered at home or in an institutional setting are guided by the Association Québécoise des Soins Palliatifs. CLSC's use their existing

data base (Régie d'assurance médicale du Québec, RAMQ) to monitor service delivery to palliative care clients. Medications are provided by the Quebec Drug Plan on a co-payment basis that is dependent on the patient's income.

To date, there is no provincial database that accounts for the number of palliative care clients in the province receiving care at home or an institution by the sex of the client.

3. Nova Scotia

Home care in Nova Scotia dates back to 1988 with the implementation of the Co-ordinated Home Care Program. On June 1, 1995, the program was replaced by Home Care Nova Scotia (Provincial and Territorial Home Care Programs, 1999). During the same year, home care programs in the four regions added hospital-in-the-home, but palliative care clients use chronic care services instead.

Since 1995, some changes have been made, mainly to the system's administration and delivery mechanisms. With the change of government in January 2001, nine District Health Councils (DHCs) have been created, replacing the existing four health regions in the province. Although a Departmental Committee has been established to examine the integration of health services in the nine DHCs, home care service delivery continues to be provided through four Regional Home Care Offices (MacDonald, Oct. 23, 2001). Despite their operational authority, all funding decisions, planning and administration are governed under the direction of the Department of Health.

Although Nova Scotia does not have a specific act governing the delivery of health care at home, the *Homemaker Services Act (1981)* and the *Co-ordinated Home Care Act (1990)* provide the direction for their delivery (Provincial and Territorial Home Care Programs, 1999). Terminally ill clients are identified as "palliative." The services that are responsive to their needs are delivered by the chronic care component of the provincial Home Care Program. Referral to the home care program is based on assessed need from a community nurse or family. Although nursing services are provided at no fee, home support services may be provided at a monthly fee.

While there is no provincial database that collects information on the number of terminal clients receiving care at home or an institution, each of the DHCs provided an approximation of the total number of clients in the fiscal year 2000/01. As shown in Table 2, more (52.1%) patients received care in an institutional setting where they died compared to 39.8% who died at home. No data were available on the sex of the clients.

Table 2
Number and Percent of Palliative Care Clients in Nova Scotia by Care Setting,
Fiscal Years 2000/2001

Place of Care	Total (percent)
Home	880 (39.8%)
Institution (home, hospital, facility)	1151 (52.1%)
No distinction of care setting made	179 (8.1%)
Total	2210

Table Notes:

1. The data in each category represent an approximation of the total number of palliative care clients in the province. The data shown are an aggregate of the total number of clients receiving care in each of the nine District Health Councils. The information was provided by each DHC and was collected for the purposes of this study.
2. Fiscal year begins April 1 and ends March 31.
3. Place of care represents place of death.

D. Participants

Eighty-nine interviews were conducted with caregivers from three different provinces in Canada (30 from British Columbia, 31 from Nova Scotia and 28 from Quebec). Four caregivers completed two interviews with regard to two different patients. All 89 interviews were retained for the qualitative analysis, but the data generated from these eight questionnaires were removed from all statistical analyses as their inclusion would violate basic statistical assumptions. Data collected from 28 caregivers from British Columbia, 24 caregivers from Quebec and 29 caregivers from Nova Scotia were included in all of the quantitative analyses (total = 81).

There was a roughly equal representation of male and female caregivers ($\bar{n}$ = 40, 49.4% and $\bar{n}$ = 41, 50.6%, respectively; see Table 3). There were slightly more caregivers of cancer patients than AIDS patients ($\bar{n}$ = 45, 55.6% and $\bar{n}$ = 36, 44.4%, respectively) and slightly more informal caregivers than formal caregivers ($\bar{n}$ = 48, 59.3% and $\bar{n}$ = 33, 40.7%, respectively). Most caregivers resided in large urban municipalities (Greater Vancouver Regional District, Halifax Regional Municipality and Montreal); however, a small sub-sample of caregivers in rural communities across Nova Scotia participated due to sampling difficulties, particularly for those who cared for an AIDS patient.

Caregivers' ages ranged from 29 to 81 years with an average age of 50 years (SD = 12.17). One-third of caregivers indicated that they were single (see Table 4), while 41% indicated that they were either married ($\bar{n}$ = 22; 27.2%) or widowed ($\bar{n}$ = 11; 13.6%). Informal caregivers only were asked about the nature of their relationship to their patient. In roughly one-quarter of the cases, the nature of the relationship was spousal ($\bar{n}$ = 13; 27.7%); however a significant number of participants indicated that their patient was their friend ($\bar{n}$ = 16; 34.0%) or other family member such as a parent, child or in-law relative ($\bar{n}$ = 14; 29.8%).

Table 3
Frequencies: Region (British Columbia, Quebec, Nova Scotia) x Diagnosis
(Cancer, AIDS) x Caregiver Status (Informal, Formal) x Sex (Male, Female)

	Males		Females		Total	
	n	%	N	%	n	%
British Columbia (BC)						
Informal						
Cancer	4	14.3	4	14.3	8	28.6
AIDS	4	14.3	5	17.9	9	32.1
Informal Total	8	28.6	9	32.1	17	60.7
Formal						
Cancer	3	10.7	4	14.3	7	25.0
AIDS	3	10.7	1	3.6	4	14.3
Formal Total	6	21.4	5	17.9	11	39.3
<i>TOTAL for BC</i>	14	50.0	14	50.0	28	100.0
Quebec (QC)	n	%	N	%	n	%
Informal						
Cancer	4	16.7	4	16.7	12	50.0
AIDS	4	16.7	2	8.3	6	25.0
Informal Total	8	33.3	6	25.0	14	58.3
Formal						
Cancer	2	8.3	4	16.7	6	25.0
AIDS	2	8.3	2	8.3	4	16.7
Formal Total	4	16.7	6	25.0	10	41.7
<i>TOTAL for QC</i>	12	50.0	12	50.0	24	100.0
Nova Scotia (NS)	n	%	N	%	n	%
Informal						
Cancer	4	13.8	5	17.2	9	31.0
AIDS	4	13.8	4	13.8	8	27.6
Informal Total	8	27.6	9	31.0	17	
Formal						
Cancer	3	10.3	4	13.8	7	24.1
AIDS	3	10.3	2	6.8	5	17.2
Formal Total	6	20.6	6	20.6	12	41.3
<i>TOTAL for NS</i>	14	48.3	15	51.7	29	100.0
TOTAL PARTICIPANTS	40	49.4	41	50.6	81	100.0

Table Note: For each region (B.C., Quebec and Nova Scotia), percentages represent number of participants/total number of participants in each region. For total participants, percentages represent number of participants/total number of participants (all regions).

Table 4
Caregiver Profile (N = 81)

Variable	<u>n</u>	<u>%</u>
Marital Status		
Single	26	32.1
Married	22	27.2
Widowed	11	13.6
Divorced	6	7.4
Separated	2	2.5
Common-law	9	11.1
Gay marriage	5	6.2
Relationship with Patient ^a (Informal Only; <u>n</u> = 47)		
Spouse/partner	13	27.7
Parent	2	4.3
Child	8	17.0
Relative	4	8.5
Friend	16	34.0
Volunteer	4	8.5
Education		
No high school	1	1.2
High school	28	34.6
Some university/college	6	7.4
University/college degree	44	54.3
Technical school	1	1.2
Other	1	1.2
Caregiver lives with patient ^b	30	37.0

Table 4 Continued on next page...

Table 4 Continued...

Variable	<u>n</u>	%
Gross Family Income (Informal Only; <u>n</u> = 31)		
0 - 9,999	1	3.2
10,000 - 19,999	2	6.5
20,000 - 29,999	3	9.7
30,000 - 39,999	6	19.4
40,000 - 49,999	7	22.6
50,000 - 59,999	5	16.1
60,000 - 69,999	1	3.2
70,000 - 79,999	0	0.0
80,000 - 89,999	0	0.0
90,000 - 99,999	2	6.5
100,000 +	4	12.9
Gross Personal Income (Informal Only; <u>n</u> = 45)		
0 - 9,999	10	23.3
10,000 - 19,999	3	7.0
20,000 - 29,999	13	30.2
30,000 - 39,999	10	23.3
40,000 - 49,999	1	2.3
50,000 - 59,999	0	0.0
60,000 - 69,999	5	11.6
70,000 - 79,999	0	0.0
80,000 - 89,999	0	0.0
90,000 - 99,999	0	0.0
100,000 +	1	2.3

Table Notes:

^a Significant difference by diagnosis, χ^2 (7, n = 47) = 33.43, $p < .00$

^b Significant difference by caregiver status, χ^2 (1, N = 81) = 12.25, $p < .001$

Caregivers of cancer patients were more likely than caregivers of AIDS patients to indicate that they were the patient's spouse or that they were related to the patient. Caregivers of AIDS patients were more likely to indicate that their relationship with the patient constituted a friendship, χ^2 (7, n = 47) = 33.43, $p < .00$.

Thirty-seven percent of participants (n = 30) indicated that they lived with their patient. Informal caregivers were more likely than formal caregivers to indicate that they lived with their patient, (n = 25; 52.1% of informal caregivers versus n = 5; 15.2% of formal caregivers), χ^2 (1, N = 81) = 12.25, $p < .001$.

The majority of caregivers (89%) indicated that they either had a high school diploma ($n = 28$, 34.6%) or a university or college degree ($n = 44$, 54.3%). There were no sex differences and no differences between formal and informal caregivers in level of education.

Half of the informal caregivers reported working either full-time ($n = 16$; 33.3%) or part-time ($n = 10$; 20.8%). Roughly half of the informal caregivers ($n = 13$, 53.5%) reported an annual personal income below \$20,000. Formal caregivers were most likely to be employed by either a home care program ($n = 15$; 45.5%) or a community-based organization ($n = 11$; 33.3%). The rate of pay varied greatly, ranging from \$4.70 per hour to \$31.00 per hour, with an average rate of pay equal to \$16.91 per hour ($SD = 8.45$). Formal caregivers of cancer patients reported a significantly higher hourly rate of pay compared to formal caregivers of AIDS patients, $M = \$19.49$, $SD = 8.29$ versus $M = \$13.15$, $SD = 7.52$, $t(25) = 2.02$, $p < .05$.

E. Recruitment

Participants were recruited using a selective sampling procedure. A selective sampling technique was employed in order to have roughly equal representations of male and female caregivers, informal and formal caregivers, and caregivers of cancer patients and AIDS patients.

The eligibility criteria for inclusion in the present study were as follows:

- Died at home or in a hospital no more than 72 hours (three days) prior to death;
- Received palliative care at home in their last month of life; and
- Home death occurred within the past three years.

The Home Care Programs/Continuing Care Programs in all three provinces provided recruitment assistance. Additional methods were also utilized in each provincial study site. Various challenges of recruitment occurred and were regionally specific.

1. British Columbia

The Palliative Care Unit in a general hospital located in the greater Vancouver area provided the researchers with a list of potential informal and formal caregivers of cancer patients who died at home between the years 1998 to 2001. This information was extracted from the hospital's database, which could identify the patient's location of death. A stratified sample was used, identifying each fifth patient on the list. Letters of information were mailed to the selected potential participants indicating the purpose of the study. Random calls were made two weeks later inviting their participation. Personal interviews were conducted with all participants after consent for participation was given. A different strategy was used to recruit caregivers of AIDS patients. The study was advertised in three different local newspapers inviting AIDS caregivers to participate. A further snowball technique was employed to ensure that there was equal representation of male and female caregivers.

2. Quebec

Most participants were recruited through the assistance of CLSCs in the Greater Montreal Area. Caregivers of AIDS patients were recruited via the assistance of AIDS Montreal and various Hospices in the area. Upon telephone contact with former clients' next of kin by staff personnel, the participants' contact information was

provided to the researchers. During this initial telephone contact, participants were given more information about the study and its confidentiality and anonymity. Face-to-face (the majority of interviews) or telephone interviews were scheduled in either French or English where consent to participate was made. Formal caregivers were identified from these agencies.

3. Nova Scotia

The recruitment strategy used for data collection in Nova Scotia varied according to the particular criteria (male/female, cancer/AIDS, formal/informal) being sought. Caregivers of AIDS patients (formal and informal) were largely recruited through community-based organizations such as the AIDS Coalition of Nova Scotia and personal contacts. The researchers used a snowball sampling technique to reach this population of caregivers through encouraging participants to refer other AIDS caregivers to the study. Formal and informal caregivers who had cared for cancer patients were referred to the study by the palliative home care staff at the Queen Elizabeth II Health Sciences Centre in Halifax.

F. Instrument

A synthesized questionnaire using two leading U.S. studies was derived for this study. The questionnaire was altered to reflect home health care in Canada and for AIDS and cancer diagnoses. This instrument was developed by U.S. researchers who studied the costs incurred for informal caregiving to a terminally ill family member:

Emanuel, E.J., Fairclough, D., Slutsman, J., and Emanuele, L. (2000) Understanding Economic and Other Burdens of Terminal Illness: The Experiences of Patients and their Caregivers. Annals of Internal Medicine. 132(6).

Rice, D., Fox, P., Max, W., Webber, P., Lindeman, D., Hauck, W., and Segura, E. (1993) The Economic Burden of Alzheimer's Disease Care. Health Affairs. Summer.

G. Measurements

In order to fully capture participants' experiences as caregivers, the present study combined quantitative and qualitative methodologies.

The independent variables were:

- Sex (female/male)
- Caregiver status (informal/formal)
- Region (British Columbia, Nova Scotia, Quebec)
- Diagnosis (cancer/AIDS)

The following dependent variables were measured quantitatively and/or qualitatively by participants' responses to the following questions.

1. Description of Caregiving

General

On average, how many hours did you spend caregiving each week?

Can you estimate how many hours per week you spent talking and providing emotional support to the patient in regards to their medical situation, spiritual matters, practical issues?

Caregiving Tasks

During the last month of care, did you provide assistance with the following activities of daily living and instrumental activities of daily living tasks? Can you estimate the average hours per week you spent carrying out the specific task?

Medical and Other Items Purchased

What kind of medical items did you have to purchase? (informal only)

In addition to the medical items, did the patient require additional items for their care? (informal only)

2. Support for Caregiving

Palliative Care Skills Training

Did you receive any skills training and/or other education specific to palliative care to assist you with the care that you provided?

Use of Social Services

What social services did you use in the last month to help care for your patient?

Other Informal Assistance and Support

Who else helped with providing care to your patient?

Who provided you with the most support during your caregiving?

Did your employer provide you with any support while caring for your patient? (formal only)

3. Economic Costs of Caregiving

Lost Income

If employed, did you work fewer hours as a result of caregiving? (informal only)

If yes, did you earn less money as a result of working fewer hours? (informal only)

Did you have to retire early or stop working because of your patient's illness? (informal only)

Did friends or family members reduce their working hours, change their job or stop working as a result of caregiving? (informal only)

Out-of-Pocket Expenses

How much did you pay, out-of-pocket, for medical items in the last month of care?

How much did you pay, out-of-pocket, for additional items in the last month of care?

How much did you pay, out-of-pocket, for social services in the last month of care?

Have you incurred any other out-of-pocket expenses in the last month of caregiving for your patient?

Compensation

Did you receive any compensation for the care you provided? (informal only)

Did you have to leave your own home in order to provide this care?

Were you paid for the travel time? (formal only)

Cost of Medication

Do you know what the charge was for the patient's medication?
Who paid for the costs of the medications?

4. Other Costs of Caregiving

Did your experience of caregiving impact on you physically?
Did your experience of caregiving impact on you emotionally?
Did your experience of caregiving impact on you mentally?
Did your experience of caregiving impact on you in terms of your family responsibilities?
Did your experience of caregiving impact on you in terms of your personal life?
Did your experience of caregiving have any other impact on you?

5. Perceived Costs for Other Caregivers

Did caring for the patient result in any emotional and/or economic hardship for the patient's family and/or friends?

6. Benefits of Caregiving

Meaning to Life

Did you find that taking care of the patient gave meaning to your life?

Relationship with Patient

Did the experience affect your relationship with [patient's name] positively or negatively?

Acknowledgement of Caregiving Effort

Did the patient acknowledge your caregiving effort?

Religion and Spirituality

Did religion or spirituality provide you with any comfort?

In addition, caregivers were also asked the following questions:

Reflecting back to when you were providing care, what (if anything) would you have done differently?

In general, what was the most difficult aspect of providing palliative care for you?

In general, what was the most positive and rewarding aspect of providing palliative care for you?

In your opinion, what would make the palliative caregiving process more effective and/or more satisfying?

H. Methods of Analysis

1. Statistical Data Analysis

Frequencies and descriptive statistics were generated in order to describe both caregivers' and patients' background. Cross-tabulations were calculated with the categorical dependent variables. Chi-squares are reported where significant findings were found.

T-tests were conducted on the continuous dependent variables to investigate differences by sex, caregiver status and diagnosis. One-way analyses of variance (ANOVA) were conducted on the continuous dependent variables to investigate regional differences. Univariate ANOVAs were conducted (selectively) on the continuous dependent variables to explore interactions between the independent variables. Only findings significant at the $p < .05$ are reported.

2. Qualitative Analysis

The basic purpose of qualitative research is to generate a rich, detailed portrait of phenomena in their natural settings in terms of the meanings people bring to them (Denzin & Lincoln, 1994). The qualitative analysis involved describing the common themes and patterns in the experiences of caregivers. This was done by constructing an indexing system for all data. The data were then organized by themes that emerged from the data. Themes were identified by sorting all the data into logical groupings. Each grouping was individually examined using an iterative process. That is, the data were revisited twice to ensure accuracy and comprehensiveness.

In the final reporting, every attempt was made to present a balanced analysis between the description of the participant's experiences and the interpretation of these experiences. The results of the qualitative analysis were then compared and combined with the quantitative data findings. This method of mixing quantitative and qualitative data yields a more comprehensive analysis.

3. Economic Analysis

This study uses a broad economic costing framework that takes into account a wide variety of "costs" and benefits, and acknowledges explicitly that those costs and benefits may be gendered and affected by diversity issues. This study augments traditional health economic costing categories by giving equal consideration to the social, physical, and emotional and psychological costs *and benefits* that are most often reported during caregivers' experiences of their caregiver role. This approach values and attempts to measure the aspects of caregiving that are not only economic, but are, in addition, measurable in terms of social, psychological or spiritual costs. In these ways, this study expands the scope of measurable effects of caregiving.

This study utilizes both quantitative and qualitative data to derive comprehensive information from caregivers about their experiences and the personal impact of these experiences. In addition, some of the information given in the interviews (such as hours spent as an informal caregiver) was quantified based on assumptions, in order to ascribe an economic value to such efforts. In these ways, the notions of economic costing are expanded and applied to an extended array of "costs" and benefits, as reported by the caregivers.

A traditional health economics framework examines tangible and intangible costs. Tangibles are items in which a dollar figure can be derived; whereas, intangibles are items such as pain and suffering that are more difficult to quantify and cost. Tangibles include direct costs of caring that are incurred while providing basic necessities such as food, shelter, clothing, health care, transportation and service costs. Indirect costs of caring are measured in terms of what health economists term "opportunity costs." These opportunity costs are areas in which a dollar value can be assigned in order to understand the income that the caregiver forgoes when providing

care (Foulke, Cooper and Butler, 1993). Foulke et al. (1993) argue that it can be very costly for caregivers who must arrange their work and family lives to fit their caregiving duties (Foulke et al., 1993).

IV. Results

A. Patient Profile

Caregivers were more likely to report caring for male patients than female patients ($n = 52$; 64.2% and $n = 29$; 35.8%, respectively, see Table 5). Further, there were significantly fewer female AIDS patients ($n = 2$) than male AIDS patients ($n = 34$), female cancer patients ($n = 27$), and male cancer patients ($n = 18$), $\chi^2 (1, n = 83) = 29.65, p < .00$.

Table 5

Patient Profile (N = 81): Diagnosis (Cancer, AIDS) x Caregiver Status (Informal, Formal) x Patient Sex (Male, Female)

Status x Diagnosis	Patient Sex ^a			
	Male		Female	
	n	%	n	%
Informal				
Cancer	5	6.2	20	24.7
AIDS	21	25.9	2	2.5
Total Informal	26	32.1	22	27.2
Formal				
Cancer	13	16.0	7	8.6
AIDS	13	16.0	0	0.0
Total Formal	26	32.0	7	8.6
TOTAL	52	64.2	29	35.8

Table Notes: Percentages = number of participants/total number of participants.

^aThere were significantly fewer female AIDS patients compared to male AIDS patients, $\chi^2 (1, N = 81) = 29.65, p < .000$. Additionally, there were more informal caregivers caring for female cancer patients than male cancer patients, $\chi^2 (1, N = 81) = 27.60, p < .000$.

The average age at death of the patients under participants' care was 60 years ($SD = 18.54$). The age of patients ranged from 29 to 101 years. Male patients were significantly younger than female patients at their death ($M = 53.83$; $SD = 18.51$ and $M = 70.86$; $SD = 12.86$; $t(79) = 4.40, p < .05$). As expected, AIDS patients died at a younger age than cancer patients, $M = 43.33$; $SD = 10.39$ and $M = 73.20$; $SD = 11.56$; $t(79) = 12.08, p < .00$.

The majority of patients ($n = 61$; 80.3%) were identified as Caucasian or White (see Table 6). According to participants' reports, half of the patients under their care were either married or widowed, while 28.4% were single and/or lived alone (33.3%). Nearly one quarter (23.5%) of patients reportedly lived with one of their children who provided them with care. In terms of education, 79.1% of patients had either a high school education ($n = 29$; 43.3%) or a university or college degree ($n = 24$; 35.8%).

Table 6
Patient Profile (N = 81)

<u>Variable</u>	<u>n</u>	<u>%</u>
Marital Status		
Single	23	28.4
Married	24	29.6
Widowed	17	21.0
Divorced	4	4.9
Common-law	7	8.6
Gay marriage	6	7.4
Living Arrangements		
Living alone	27	33.3
With spouse only	27	33.3
Spouse and relatives	4	4.9
Spouse and non-relatives	1	1.2
Living with child caregiver	19	23.5
Other	3	3.7
Ethnicity (<u>n</u> = 76)		
Caucasian/White	61	80.3
Native American/Canadian	2	2.6
Other	13	17.1
Education (<u>n</u> = 67)		
No high school	5	7.5
High school	29	43.3
Some university/college	8	11.9
University/college degree	24	35.8
Technical school	1	1.5

Table 6 Continued on next page...

Table 6 Continued...

Variable	<u>n</u>	<u>%</u>
Income (<u>n</u> = 62)		
0 - 9,999	11	17.7
10,000 - 19,999	15	24.2
20,000 - 29,999	15	24.2
30,000 - 39,999	7	11.3
40,000 - 49,999	1	1.6
50,000 - 59,999	3	4.8
60,000 - 69,999	3	4.8
70,000 - 79,999	5	8.1
80,000 - 89,999	0	0.0
90,000 - 99,999	1	1.6
100,000 +	1	1.6

Slightly greater than half (n = 45, 55.6%) of participants reported that their patient had multiple sources of income. Patients were most likely to receive income from a pension (n = 39, 48.1%), followed by Old Age Security (n = 28, 34.6%), disability (n = 22, 27.2%), savings (n = 17, 21.0%), private insurance (n = 15, 18.5%), investment income (n = 13, 16.0%) and other sources (n = 13, 16.0%). Few patients derived income from social security (n = 3), guaranteed income (n = 4) and employment (n = 1).

The vast majority (n = 69, 85.2%) of participants indicated that the government paid for their patient's health care. Nine participants (11.1%) reported their patients had private insurance. Few participants reported that their patient had their health care provided for by their partner (n = 1), friends (n = 1), family members (n = 2), or that the patient paid for their own health care (n = 3). Only 7 of the 83 patients (1%) had their health care paid for by multiple sources.

B. Description of Caregiving

1. General

The hours of caregiving per week reported by participants ranged from 1 hour/week to 168 hours/week, with an average of 57 hours/week (SD = 62.26, see Table 7). Not surprisingly, informal caregivers spent three times longer providing care to their patient compared to formal caregivers, spending roughly 79 hours per week versus 26 hours per week providing care, $t(79) = 4.10$, $p < .00$. There was a significant interaction between diagnosis of patient and status of caregiver for the average number of hours per week engaged in caregiving tasks. Informal caregivers of cancer patients spent the most time engaging in caregiving tasks (M = 98.2, SD = 63.62),

while formal caregivers of cancer patients spent the least amount of time caregiving ($M = 17.15$, $SD = 36.83$).

Table 7
Caregiver Tasks (Number of Tasks & Hours/Week) x Independent Variables

Variable	Hours Caregiving		Hours Providing Emotional Support		Number of Caregiving Tasks		Hours Engaged in Caregiving Tasks	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Sex								
Male	56.1	60.5	22.3	32.5	7.3	3.6	39.4	43.0
Female	58.8	65.0	24.4	32.7	7.4	4.2	42.3	46.6
Caregiver Status ^a								
Informal	79.0	65.1	34.5	37.5	8.9	3.6	52.6	44.9
Formal	26.2	42.0	7.8	12.1	5.2	3.3	22.7	38.1
Diagnosis								
Cancer	62.2	66.7	24.8	33.8	7.0	3.7	34.6	37.8
AIDS	51.5	56.6	21.6	30.9	7.9	4.1	48.7	51.4
Region								
BC	56.5	57.1	20.0	19.3	8.6	4.0	48.0	48.7
QC	62.6	66.4	31.1	43.5	6.8	3.3	43.8	49.0
NS	54.1	65.4	20.9	33.1	6.7	4.1	31.9	36.2
TOTAL	57.5	62.3	23.3	32.4	7.4	3.9	40.8	44.6

Table Notes: Responses under "Hours Caregiving" derived from the question "On average, how many hours did you spend caregiving each week?" Responses under "Hours Providing Emotional Support" derived from question "Can you estimate how many hours per week you spent talking and providing emotional support to the patient in regards to their medical situation, spiritual matters, practical issues?" Responses under "Number of Caregiving Tasks" calculated from question "During the last month of care, did you provide assistance with the following activities of daily living and instrumental activities of daily living tasks?" Responses under "Hours Engaged in Caregiving Tasks" calculated from question "Can you estimate the average hours per week you spent carrying out the specific task?"

^a Significant difference in average hours per week spent caregiving, $t(79) = 4.10$, $p < .00$; and hours per week spent providing emotional support, $t(72) = 3.82$, $p < .00$

The average number of hours spent providing emotional support to patients was 23.32 hours/week (range 0 to 168; $SD = 32.36$). Informal caregivers reported spending significantly more time providing such support compared to the formal caregivers with 35 hours per week versus 8 hours per week, $t(72) = 3.82$, $p < .000$. Although no significant gender differences were noticed in the hours spent caregiving (58.8 hours for females and 56.1 hours for males), it appears that female caregivers spend on

average a slightly greater amount of time performing the tasks compared to males (42.3 hours versus 39.4 hours for males).

2. Caregiving Tasks

In terms of specific caregiving tasks performed, participants were most likely to report engaging in the following tasks (see Table 8): giving out medication (69%), grooming patient (64%), ambulation (61%), transferring patient from bed, toilet, chair, etc. (61%), and food preparation (58%). Providing transportation services and doing outdoor maintenance were infrequently mentioned as caregiving tasks (20% and 14%, respectively).

Table 8
Caregiver Tasks: Frequencies and Average Hours/Week

Task	Frequency		Hours/Week	
	<u>n</u>	<u>%</u>	<u>M</u>	<u>SD</u>
Grooming/Hygiene	52	64.2	5.5	5.7
Ambulation (movement)	49	60.5	6.9	7.1
Transfer (bed, chair, toilet)	49	60.5	7.4	13.0
Bathing	39	48.1	5.3	6.0
Dressing	39	48.1	3.1	3.4
Feeding	35	43.8	7.3	5.9
Food preparation	47	58.0	8.6	7.4
Housekeeping	37	45.7	6.5	5.6
Transportation	16	19.8	4.8	2.9
Shopping	37	45.7	3.5	3.0
Financial/legal affairs	27	33.3	2.7	2.4
Social/recreation	30	37.0	5.1	4.4
Outdoor maintenance	11	13.6	2.7	1.6
Medications	56	69.1	5.8	8.1
Management of behavioural problems	37	45.7	8.0	9.0
Other tasks	37	45.7	8.6	13.9

Informal caregivers reported engaging in a greater number of caregiving tasks compared to formal caregivers, nine versus five, $t(79) = 4.59$, $p < .00$. In terms of individual tasks, informal caregivers were more likely to engage in the following tasks: transfer of patient, feeding, food preparation, housekeeping, transportation, shopping, taking care of financial/legal affairs, social/recreational activities, outdoor maintenance, and management of behavioural problems.

Two gender differences were found. Female caregivers were more likely to report dressing their patient, $\chi^2 (1, N = 81) = 3.62, p < .05$, and reported spending less time attending to the legal and/or financial affairs of their client, $t (16) = 2.16, p < .05$, compared to male caregivers.

When considering formal and informal caregivers separately, gender differences were only found among informal caregivers. Female caregivers were more likely to report dressing their patient, $\chi^2 (1, n = 48) = 6.93, p < .01$. Within formal caregivers only, there were no significant gender differences in caregiving tasks performed.

There were significant differences between female informal and female formal caregivers in caregiving tasks performed. Female informal caregivers were more likely than female formal caregivers to report preparing food for their patient, $\chi^2 (1, n = 41) = 13.11, p < .001$, to engage in housekeeping tasks, $\chi^2 (1, n = 41) = 6.31, p < .05$, to attend to the financial/legal affairs of their patient, $\chi^2 (1, n = 41) = 10.34, p < .01$, to do outdoor maintenance, $\chi^2 (1, n = 41) = 7.15, p < .05$, and to manage behavioural problems, $\chi^2 (1, n = 41) = 7.19, p < .01$. Male formal and male informal caregivers were equally likely to perform all of these tasks.

A greater proportion of caregivers of AIDS patients, compared to caregivers of cancer patients indicated that they fed their patient, ($n = 20, 57.1\%$ versus $n = 15, 33.3\%$). Caregivers of patients with cancer were more likely than caregivers of AIDS patients to indicate there were other tasks they undertook that were not mentioned elsewhere in the questionnaire, $\chi^2 (1, N = 81) = 6.08, p < .05$; however, this was only the case for formal caregivers.

Regional differences were uncovered for bathing, transportation, handling of financial/legal affairs, the management of behavioural problems, and other caregiving tasks. Caregivers in B.C. were more likely than caregivers in both Quebec and Nova Scotia to report bathing their patient, $\chi^2 (2, N = 81) = 7.13, p < .05$, providing transportation for their patient, $\chi^2 (2, N = 81) = 9.03, p < .05$, and managing behavioural problems, $\chi^2 (2, N = 81) = 16.38, p < .00$. Caregivers in B.C. and Nova Scotia were more likely than caregivers in Quebec to report attending to the financial and legal affairs of their patient, $\chi^2 (2, N = 81) = 8.85, p < .05$. Caregivers in Quebec were more likely than caregivers in B.C. and Nova Scotia to indicate there were "other" caregiving tasks they performed, $\chi^2 (2, N = 81) = 6.14, p < .05$.

Additionally, when considering formal and informal caregivers separately, informal caregivers from B.C. and Quebec were both more likely than informal caregivers in Nova Scotia to report feeding their patient as one of their caregiving tasks, $\chi^2 (2, n = 47) = 7.17, p < .05$. Further, formal caregivers from B.C. were more likely than formal caregivers from Nova Scotia and Quebec to report performing housekeeping chores, $\chi^2 (2, n = 33) = 8.75, p < .05$, and providing shopping services for their patient, $\chi^2 (2, n = 33) = 7.22, p < .05$.

3. Medical and Other Items Purchased

The total number of medical items purchased by informal caregivers ranged from zero to nine with an average of four items ($SD = 2.44$). The medical items most frequently purchased by caregivers (see Table 9) included a hospital bed ($n = 32, 68.1\%$), toilet

seats ($n = 30$; 63.8%), shower/bath seats ($n = 28$; 59.6%), wheelchair ($n = 25$; 53.2%), and canes, crutches and walkers ($n = 19$; 40.4%).

The total number of additional items purchased by informal caregivers ranged from zero to seven with an average of three items ($SD = 1.82$). The additional items most frequently purchased included special drinks ($n = 29$; 61.7%), incontinence products ($n = 28$; 60.9%), special bedding items ($n = 20$; 42.6%), and special food ($n = 20$; 42.6%). There were no significant gender differences in the purchase of medical and other items.

Table 9
Medical and Additional Items Purchased by Informal Caregivers ($n = 47$)

Medical Items	<u>n</u>	<u>%</u>
Any medical item	41	87.2
Hospital bed	15	31.9
Wheelchair	25	53.2
Cane/crutches	19	40.4
Shower/bath seat	28	59.6
Patient lifter	3	6.4
Medical gloves	18	38.3
Bed pans	15	31.9
Toilet seat	30	63.8
Hand rails	16	34.0
Other medical items	18	38.3
Additional Items	<u>n</u>	<u>%</u>
Special clothing	13	27.7
Special foods	20	42.6
Special drinks	29	61.7
Incontinence products	28	60.9
Alternative or complementary therapies	11	23.9
Entertainment or recreation	17	36.2
Special bedding items	20	42.6
Other items not listed	13	27.7

Caregivers of AIDS patients were more likely than caregivers of cancer patients to purchase special food, $\chi^2 (1, n = 47) = 4.70, p < .05$, and special drinks, $\chi^2 (1, n = 47) = 7.40, p < .01$. Additionally, some regional differences in the purchase of medical and other items did exist. Only informal caregivers from B.C. and Nova Scotia reported using alternative therapy with their patient, $n = 6, 37.50\%$ and $n = 5, 29.41\%$,

(Quebec: $\underline{n} = 0$); $\chi^2 (1, \underline{n} = 48) = 9.91, p < .01$. Informal caregivers from Nova Scotia were significantly less likely than caregivers from B.C. and Quebec to report the purchase of special bedding for their patient, $\underline{n} = 3, 17.65\%$ versus $\underline{n} = 9, 56.25\%$ and $\underline{n} = 9, 56.25\%$, respectively, $\chi^2 (1, \underline{n} = 49) = 7.22, p < .05$.

C. Support for Caregiving

1. Palliative Care Skills Training

Sixty-one percent of the participants ($\underline{n} = 49$) indicated that they received skills training in palliative care. Formal caregivers were more likely than informal caregivers to have received such training, $\chi^2 (1, \underline{n} = 81) = 5.60, p < .05$.

The majority of formal caregivers (76%) reported "specialized nurse training in palliative care," "palliative care courses and conferences," or "social homemaker training." One formal caregiver reported that the four-day course she took on caring for people in the terminal phase was inadequate. She said, *"There was too much content within too little time. It was difficult to retain. I want to get 'real' training in palliative care."*

In contrast, only 50% of informal caregivers reported such training or education. Most mentioned "casual" or "informal" training by nurses or other health professionals: *"The nurse gave bedside training on medicine, morphine"* (cancer informal male – British Columbia), and *"The nurse explained to me how to rub her and how to move her"* (cancer informal female – Nova Scotia).

Many of the AIDS informal caregivers talked about gaining a specific knowledge through their experience with the AIDS community:

- *"I'm a volunteer with [agency's name] so as part of the home care team, we meet to discuss 'how to deal with caring for AIDS/HIV' three days a week. Speakers come in and we have in-house meetings continually to talk about our own experiences."* (AIDS informal female – British Columbia)
- *"I've taken care of my friends who also died of AIDS. I knew what to expect."* (AIDS informal male – Montreal)
- *"I am HIV myself so I just know what to do through counselling."* (AIDS informal male – British Columbia)

2. Use of Social Services

On average, caregivers used 3.23 social services ($SD = 2.28$), ranging from 0 to 18 services used. Among the services most likely to be used included the following: skilled nursing services (79%), shopping service (62%), and homemaking or housekeeping services (61%). See Table 10 for the frequency of use of each social service.

Female caregivers in general were less likely than male caregivers to obtain individual or family counselling for their patient, $\underline{n} = 1, 2.4\%$ vs. $\underline{n} = 10, 25.0\%$, respectively; $\chi^2 (1, \underline{N} = 81) = 9.97, p < .01$. This finding only generalized to formal caregivers not

informal caregivers. Female and male informal caregivers were equally likely to obtain counselling services for their patient.

Table 10
Social Services Used to Help Care for Relatives and Hours/Month Used

Task	Frequencies/ Percentages	
	<u>n</u>	%
Homemaker/housekeeper	49	60.5
In-home attendant/companion	7	8.6
Home-delivered/congregate meal	4	4.9
Shopping service	50	61.7
Telephone network	3	3.7
Transportation services	4	4.9
Skilled nursing services	64	79.0
Adult day health care	2	2.5
Live-in attendant	4	4.9
Physical, occupational or speech therapy	11	13.6
Individual/family counselling	11	13.6
Support group	6	7.4
In-patient respite care	13	16.0
Financial/legal	2	2.5
Massage therapist	6	7.4
Naturopath	2	2.5
Chiropractor	1	1.2
Other services	23	28.4

Among informal caregivers only, females were more likely than males to have obtained massage therapy for their patient compared to male caregivers ($\underline{n} = 5$; 20.83% versus $\underline{n} = 0$; 0.00%), $\chi^2 (1, \underline{n} = 48) = 7.51, p < .05$.

Informal caregivers were more likely to use a shopping service compared to formal caregivers, $\underline{n} = 47$; 97.91% vs. $\underline{n} = 3$; 9.09%, $\chi^2 (1, \underline{N} = 81) = 77.96, p < .00$. Formal caregivers, however, were more likely to use in-patient respite care compared to informal caregivers, $\underline{n} = 10$, 30.3% vs. $\underline{n} = 3$, 6.25%; $\chi^2 (1, \underline{N} = 81) = 8.43, p < .01$.

Skilled nursing services were used more often for cancer patients than AIDS patients, $\underline{n} = 39$, 86.7% versus $\underline{n} = 69.4\%$, $\chi^2 (1, \underline{N} = 81) = 3.58, p < .05$. Additionally, caregivers of cancer patients were more likely than caregivers of AIDS patients to

indicate that they used other service providers, $n = 17$, 37.8% versus $n = 6$, 16.7%, $\chi^2 (1, N = 81) = 4.55, p < .05$.

Regional differences in the use of social services were found. Transportation was a service used only in Nova Scotia ($n = 4$; 13.8%), $\chi^2 (2, N = 81) = 8.60, p < .05$. This was true only for informal caregivers, not formal caregivers. In-patient respite care was more likely to be used in Nova Scotia ($n = 11$, 62.1%) compared to B.C. ($n = 1$; <1%) and Quebec ($n = 1$; <1%), $\chi^2 (2, N = 81) = 15.92, p < .00$. Finally, physical, occupational and/or speech therapy was more often used in Quebec ($n = 9$, 37.5%) than B.C. ($n = 1$; 3.6%) and Nova Scotia ($n = 1$; 3.4%), $\chi^2 (2, N = 81) = 15.28, p < .00$.

3. Other Informal Assistance and Support

Twelve percent of caregivers indicated that no one else had helped with providing care to the patient. Nearly half (51%) reported that another family member had assisted, 40% reported that friends had helped and 23% reported that either volunteers or paid professionals were involved in the caregiving of the patient. In most cases where someone else did assist, more than one other person was involved. Often there was an entire group of caregivers. As one cancer informal female caregiver from Quebec put it, *"everyone helped out depending on his/her ability, running errands and helping with arrangements."*

Twenty percent of caregivers reported that no one has supported them through their experience. In the words of a cancer informal female caregiver from Nova Scotia: *"I had no time for a normal support network. It was an isolating time."*

In comparison, 51% had support from their own family (27%) or their patient's family (23%), 14% from friends, and 20% answered that they had received their greatest support from paid professionals (e.g., nurses, social workers). The base of support for informal and formal caregivers differed. Of those reporting some support, the majority (88%) of informal caregivers reported support from family (53%) and/or professional caregivers (35%), while 53% of all formal caregivers reported that most of their support came from their patient's family.

Fifty-eight percent of all formal caregivers also reported that they did not receive any support from their employers. Eleven percent of these did not feel that they needed it, but explained that if they did, help would be readily available. According to one cancer formal male caregiver in Quebec: *If I needed it help was available through the Employee Assistance Program.* One cancer formal female caregiver from British Columbia did complain, however, that her employer did not act properly when they did not inform her that her patient had died: *"They didn't even tell me when she died. I complained about them not telling the home support workers when their clients die and now they make a point of telling us."* The remainder mentioned that their employers provided them with respite, information, encouragement, de-briefing and counselling.

D. Economic Costs of Caregiving

1. Lost Income

Only 15% of informal caregivers ($n = 7$) reported receiving compensation for their caregiving. Half of the participants reported working either full-time ($n = 16$; 33.3%) or part-time ($n = 10$; 20.8%). However, roughly one-quarter ($n = 11$; 22.9%) of informal caregivers reported that they had to reduce the number of hours they worked at their place of employment in order to care for their patient. Related to this finding is that 21% ($n = 10$) of informal caregivers reported earning less money as a result of their caregiving. Their responses included the following:

- *"I cancelled some jobs or I took time off some contracts because I was there."* (AIDS informal male – British Columbia)
- *"There was the cost to the business of me not being there."* (cancer informal female – Nova Scotia)

Among those who were working, many reported taking some form of leave: *"I took a cumulative leave (vacation and overtime) with employers' consent. After her death, I took one month sick leave because I was exhausted"* (cancer informal male Quebec).

Twenty-four percent ($n = 12$) of informal caregivers indicated they had to retire early in order to care for their patient. Others reported that they simply stopped working. For example:

- *"I had to stop working. It came to the point where I wasn't being adequate in either caregiving or in my full-time job so I had to see which one was more important: if I would continue by job for the money or see my friend die with dignity. My partner said we were fine financially so I quit and helped my friend. We lived off credit cards for a while."* (AIDS informal male – British Columbia)

The remainder explained that after the fact, they had to make up for lost time. According to one cancer informal female caregiver from Nova Scotia: *"I worked 14 hours a day to make up for the time I spent caregiving."*

Informal caregivers reported other persons close to the patient experienced interruptions to their work. The majority of such persons reduced their work hours (44%).

- *"We have a younger daughter who lives in San Francisco who took three weeks off. Our son took two weeks off and our older daughter took a couple of weeks off."* (cancer informal female – British Columbia)
- *"His mom had to move from Calgary; his sister was a police officer and she would come at night, so she had to give up some shift work; his boyfriend gave up his night job."* (AIDS informal male – British Columbia)

2. Out-of-Pocket Expenses

Greater than half of all caregivers ($n = 51$, 63.0%) reported having at least some out-of-pocket expenses (see Table 11). Informal caregivers were more likely than formal

caregivers to report any out-of-pocket expense, $\chi^2(1, N = 81) = 13.40, p < .00$. Caregivers from B.C. were more likely to incur out-of-pocket expenses compared to caregivers from Nova Scotia and Quebec, $\chi^2(1, N = 81) = 7.23, p < .05$.

Table 11
Out-of-Pocket Expenses

Variable	Any Expense		Medical Items		Additional Items		Social Services	
	n	%	n	%	n	%	n	%
Sex								
Male	27	67.5	6	15.0	10	25.0	8	20.0
Female	17	41.5	10	24.4	14	34.1	4	9.8
Caregiver Status ^a								
Informal	38	79.2	16	33.3	24	50.0	8	16.7
Formal	13	39.4	0	0.0	0	0.0	4	12.1
Diagnosis								
Cancer	27	60.0	12	26.7	14	31.1	7	15.6
AIDS	24	66.7	4	11.1	10	27.8	5	13.9
Region ^b								
B.C.	23	82.1	7	25.0	12	42.9	2	7.1
Quebec	13	54.2	3	12.5	3	12.5	5	20.8
Nova Scotia	15	51.7	6	20.7	9	31.0	5	17.2
TOTAL	51	63.0	16	19.8	24	29.6	12	14.8

^a Significant difference between informal and formal caregivers in any costs incurred, $\chi^2(1, N = 81) = 13.40, p < .00$, costs incurred from the purchase of medical items, $\chi^2(1, N = 81) = 19.40, p < .00$, and additional items, $\chi^2(1, N = 81) = 31.90, p < .00$

^b Significant regional differences in any costs incurred, $\chi^2(1, N = 81) = 7.23, p < .05$, costs incurred from the purchase of additional items, $\chi^2(1, N = 81) = 6.20, p < .05$

In terms of specific costs, few caregivers paid out of their own pockets for social services. Only 12 caregivers (14.8%) reported paying directly for social services for their patient. In the last month of their patient's illness, caregivers reported spending between \$25 (for a massage therapist) and \$8,300 (for skilled nursing services). Caregivers were most likely to report out-of-pocket expenses for skilled nursing services ($n = 4$). Although not statistically significant, it is interesting to note that in all four cases, the patient had cancer.

Only informal caregivers were asked about medical items (e.g., crutches, gloves, bed pans, hand rails, etc.) and additional items (e.g., special clothing, food, drinks, bedding, etc.) purchased on behalf of their patient. Many caregivers reported incurring out-of-pocket expenses as a result of needing to purchase medical items ($n = 16$, 33.3%) and other items ($n = 24$, 50%) for their patient. The amount spent purchasing medical and other items in the last month of their patient's illness varied greatly from \$16 (for special drinks) to \$20,000 (for ozone therapy). The average amount spent on medical items in the last month was roughly \$240 ($SD = 381.84$); while the average amount spent on additional items (excluding the ozone therapy) was roughly \$220 ($SD = 275.09$).

There was a significant gender difference in costs incurred. Female caregivers of AIDS patients were more likely than male caregivers of AIDS patients to purchase medical items for their patient, $n = 4$, 25.0% versus $n = 0$, 0.00%, $\chi^2 (1, N = 36) = 7.12$, $p < .05$. As expected, informal caregivers were more likely than formal caregivers to purchase out-of-pocket both medical items [$\chi^2 (1, N = 81) = 19.40$, $p < .00$] and additional items [$\chi^2 (1, N = 81) = 31.90$, $p < .00$]. There was also a regional difference in costs incurred from the purchase of additional items. Caregivers in B.C. were the most likely to purchase additional items, followed by Nova Scotia, and Quebec, $\chi^2 (1, N = 81) = 6.20$, $p < .05$.

Half of the participants ($n = 40$, 49.4%) reported other out-of-pocket expenses in addition to costs related to the purchase of social services, medical items and other items (e.g., gifts, medical items, food, travel expenses, suppositories, laundry services). Male caregivers were more likely than female caregivers to report additional out-of-pocket expenses, $\chi^2 (1, N = 81) = 4.51$, $p < .05$. Informal caregivers were more likely than formal caregivers to have other out-of-pocket expenses, $\chi^2 (1, N = 81) = 9.39$, $p < .01$. Finally, caregivers from B.C. were more likely than caregivers from Nova Scotia and Quebec to report other expenses, $\chi^2 (1, N = 81) = 7.68$, $p < .05$.

In addition to purchasing items and services for their patient, 75% of informal caregivers reported having to leave home, at their own expense, to provide care.

- *"I came from Toronto for the last four weeks."* (cancer informal female – Nova Scotia)
- *"I went to live with sister in Montreal."* (cancer informal male – Quebec)
- *"I had to quit my job and move to Vancouver, in her apartment."* (AIDS informal female – British Columbia)

Informal caregivers reported that they had to travel less far than formal caregivers to care for their patient, $\chi^2 (1, N = 81) = 15.70, p < .01$. Regional differences in distance traveled were apparent. Caregivers in B.C. indicated that they had to travel further compared to caregivers in Nova Scotia and Quebec, $\chi^2 (1, N = 66) = 16.17, p < .05$.

3. Quantifying Caregivers' Time

The self-reported wages of the formal caregivers who participated in the study were used to do a cost estimate of informal caregiver time spent in the last month of life. Wages for formal caregivers ranged from \$4.70 to \$31.00, with an average wage of \$16.91.

Informal caregivers indicated that they spent an average of 340 hours per month providing general care to their patient. This would translate into a cost ranging from \$1,600 to \$10,540 per patient per month with an average cost of \$5,750 per patient. However, when caregivers list the work task by task, the total estimate is less. For example, informal caregivers provided between \$1,081 and \$7,130 of unpaid labour per month (average = \$3,890) when asked to list task by task. The discrepancy arises due to general caregiving time not being easily categorized into tasks.

Seventy-three participants indicated that caregivers other than themselves (e.g., friends, other family members, volunteers, etc.) also provided care to their patient. Of these 73 participants, 59 provided estimates of the number of hours in the last month of care other caregivers provided support. On average, other caregivers provided 404 hours of care per month. This would translate into between \$1,900 and \$12,500 of unpaid labour provided by other, informal caregivers (average \$6,850/patient in the last month of care).

4. Compensation

Although the majority of informal caregivers incurred some personal costs as a result of their caregiving, very few ($n = 7, 14.6\%$) received some form of compensation for the care they provided. The compensation they did receive ranged from spending money for support to money left in wills to collective art and other gifts. For example:

- "His parents gave me some of his pieces of collected art, sculptures and plants."
(*AIDS informal male – British Columbia*)
- "When he passed away, I was his beneficiary." (*AIDS informal male – Nova Scotia*)

Formal caregivers were unlikely to indicate that they were compensated for any out-of-pocket expenses they incurred. However, the majority ($n = 21, 70\%$) were reimbursed for their travel expenses. With the exception of four who lived with their patient, formal caregivers travelled an average of 14 km to reach their patients. Mileage reimbursement ranged from 29-42¢/km.

5. Cost of Medication

Sixty-nine percent ($n = 56$) of caregivers indicated that they dispensed medications for their patient. Greater than half of the respondents ($n = 32, 57.1\%$) indicated that they did not know the how much their patient paid for their medication. Participants estimated that the cost of their patient's medications ranged from less than \$19 to over

\$200. Slightly more than half ($n = 13$, 54.2%) of the patients paid greater than \$200 for their medication. Participants reported that the cost of medications was paid for primarily by the government ($n = 50$, 61.7%). Other individuals paying for the cost of medications include the patients themselves ($n = 5$), family members (including partners) ($n = 7$), friends ($n = 3$), private insurance ($n = 7$), and the Cancer Society ($n = 1$).

E. Other Costs of Caregiving

Participants reported that caregiving had the largest impact on them emotionally ($n = 72$, 88.9%). They also reported an impact on their mental health ($n = 49$; 60.5%), their personal life ($n = 48$, 59.3%), their physical health ($n = 42$, 51.9%), and their family life ($n = 31$, 38.3%). One-quarter of the participants ($n = 20$; 24.7%) reported additional impacts on their life.

Overall, informal caregivers were more likely than formal caregivers to report a physical impact resulting from their caregiving activities, $n = 34$, 70.8% versus $n = 8$, 24.2%, $\chi^2 (2, N = 81) = 17.68$, $p < .00$. Female informal caregivers of cancer patients were more likely than their male counterparts to report an impact on their family life, $\chi^2 (1, n = 25) = 5.07$, $p < .05$. Female formal caregivers of cancer patients were more likely than their male counterparts to report that their caregiving had an impact on their personal life, $\chi^2 (1, n = 20) = 6.19$, $p < .05$.

Compared to female formal caregivers, female informal caregivers were more likely to report that their caregiving had an impact on their family life, $n = 3$, 16.7% versus $n = 15$; 83.3%, $\chi^2 (1, n = 41) = 8.63$, $p < .01$. Additionally, female informal caregivers were more likely to report a physical impact than female formal caregivers, $n = 19$; 86.4% versus $n = 3$; 13.6%, $\chi^2 (1, n = 41) = 16.21$, $p < .00$. These differences did not generalize to male informal and formal caregivers.

There were regional differences in the report of "other impacts" of caregiving. Caregivers in Quebec were more likely than caregivers in B.C. and Nova Scotia to report "other impacts" of their caregiving, $n = 23$, 95.8% versus $n = 11$, 39.3% and $n = 8$, 27.6%, $\chi^2 (2, N = 81) = 10.55$, $p < .01$. This was only true for formal caregivers, not informal caregivers.

Additionally, when considering formal caregivers only, caregivers in B.C. ($n = 11$, 100%) and Nova Scotia ($n = 11$, 91.67%) were more likely than formal caregivers in Quebec ($n = 5$, 50.0%) to report an emotional impact as a result of their caregiving efforts, $\chi^2 (2, n = 33) = 10.55$, $p < .01$.

F. Perceived Costs for Other Caregivers

Seventy-eight percent reported that caring for the patient resulted in any emotional hardship for family and friends. Emotional strain, the process of grief and loss, and family strife all factored in for these caregivers:

- *"The father avoided discussing their mother's situation with his sons because they were in great distress."* (cancer informal female – Nova Scotia)

- *"Family was distressed to see him failing. He was consumed with cancer. He was in a lot of pain and it was hard at the end, it was hard for the family to deal with his confusion."* (cancer informal female – Quebec)
- *"It's draining for everyone emotionally."* (AIDS formal male – Nova Scotia)

For some of the AIDS patients, emotional hardship was exacerbated by the fact that families were first learning about the patient's sexual orientation as the patient was dying:

- *"Of course, they found out that he was gay and dying at the same time."* (AIDS formal female – British Columbia)

Caregivers who did not report hardship explained that they had been prepared for the inevitability of death. As one respondent put it: *"The family, friends, and patient were all prepared. It was hard on them but they were dealing effectively with it"* (AIDS formal female – Quebec).

In general, economic hardship for the patient's family and friends was perceived by 30% of all caregivers, as evidenced by the following quotes:

- *"Economically it was a little stressful."* (cancer informal female – Quebec)
- *"She [the patient] was the breadwinner, husband couldn't work so there was no income."* (cancer formal male – Quebec)
- *"His mom was on a pension so she couldn't afford it"* (AIDS informal male – British Columbia)
- *"I'm in debt now and have to work when I could have been retired. I used all my RSPs to pay for her. I spent \$200,000 in total for rent, food, medications, therapy, my expenses."* (AIDS informal female – British Columbia)

Caregivers of AIDS patients were more likely than caregivers of cancer patients to report that the patient's family suffered economic hardship, $\underline{n} = 15$, 45.5% versus $\underline{n} = 8$, 18.2%, $\chi^2 (1, \underline{N} = 81) = 6.70$, $p < .01$.

G. Benefits of Caregiving

1. Meaning to Life

Ninety-four percent of all caregivers reported that their experience gave meaning to their lives. Caregivers consistently stated that such meaning came from making a difference in the life of another person by being there for them and by helping them to die at home. This was particularly the case with informal caregivers:

- *"When you love someone you want to do what you can and as much as you can for them. They need love, companionship and understanding."* (AIDS informal female – Quebec)

- *"When [my dad] wanted time to stay at home, I could do it. I hope some day someone will do it for me – that is the way I would want it."* (cancer informal female – British Columbia)
- *"What I did for him was important. We didn't want to be apart. We wanted to stay together until the end – with our things in the house. There is a tenderness that you can't get in a hospital, time you can't buy. This gave me some consolation."* (cancer informal female – Quebec)
- *"The role I was filling needed to be filled in order to keep the patient at home. I felt good about that."* (AIDS formal male – Nova Scotia)
- *"Hospitals cannot provide care like a family can."* (cancer informal female – Nova Scotia)

Caregivers consistently reported that they felt "privileged" to be involved and that it was a "gift" to be part of the palliative care process. Some, as evidenced in the following quote, mentioned that it was a way to care for those who had previously cared for them:

- *"It was only fitting because as a child she was the one who took care of me when my parents died. It is she who paid for my university studies. So for me, it felt like it was my turn to take care of her."* (cancer informal male – Quebec)

Many reported that the experience changed their outlook on life:

- *"I've learned how not to take things for granted and how to respect life."* (cancer formal female – Nova Scotia)
- *"I don't lose my temper anymore. I don't get stuck on the little problems in life. I know life is important and we have to prepare ourselves – we could die too."* (AIDS informal female Quebec)
- *"Life is important and I need to enjoy it more."* (cancer formal male – British Columbia)

Several caregivers explained that they became more comfortable with death and dying:

- *"It makes dying more part of life and what is natural."* (cancer formal female – Nova Scotia)
- *"Provides person with insight about death and dying. It brings a sense of reality of what it's like to die at home."* (cancer informal male – Nova Scotia)
- *"It made me less scared of death."* (AIDS informal male – Nova Scotia)
- *"He was very brave in facing death and it gave me strength to see that death is just a course of life."* (AIDS formal female – British Columbia)

A number of AIDS informal caregivers reported that the experience gave them strength to help others and become more involved in AIDS volunteer work. As two such caregivers indicated: *"That's why I'm a volunteer for AIDS organizations"* (AIDS informal male – Nova Scotia), and *"It led me to start working in the field of care and community aid"* (AIDS informal male – Quebec).

2. Relationship with Patient

Eighty-six percent of all caregivers reported that their relationship with the patient had improved throughout the process. Some examples included:

- *"It enriched our relationship. Trust was deepened and we became more intimate."* (AIDS informal male – British Columbia)
- *"We bonded closer. I still keep in touch with his family."* (AIDS formal female – British Columbia)
- *"My mother was not the type of person to tell us that she loved us... The last month she told me that she loved me. It is so beautiful what people can make us feel. She let herself go with me, she confided in me."* (cancer informal female – Quebec)
- *"It brought us closer together, knowing that time was cut short."* (cancer informal male – Quebec)
- *"He finally opened up to me at the end and it took some weight off his shoulders."* (cancer formal male – Quebec)
- *"The patient experienced caring and the caregiver experienced his openness to caring."* (AIDS formal male – Nova Scotia)

Ten percent of caregivers reported negative effects on relationships:

- *"He took it [my caregiving] for granted."* (AIDS informal male – British Columbia)
- *"He didn't want to die. I was the nearest person and [the patient's frustrations] were taken out on me."* (cancer informal female – British Columbia)
- *"We disagreed on so many things. I was frustrated because I knew about things and the patient would not trust or believe me."* (AIDS informal male – Nova Scotia)
- *"The change in mental state sometimes made her into a baby and sometimes into an enemy. It made it difficult to understand the nature of my relationship with my wife during palliative care."* (cancer informal male – Quebec)

Four percent reported a mix of the both positive and negative effects or no change whatsoever:

- *"It was a mix of both [positive and negative effects]. I was glad I could do it, but it wasn't pleasant because I was depressed."* (cancer informal male – British Columbia)
- *"I didn't care for him until he was close to death. There was no chance for a relationship."* (AIDS formal male – Nova Scotia)

3. Acknowledgement of Caregiving Effort

The vast majority (91%) of caregivers reported that their caregiving efforts were acknowledged and that patients consistently told their caregivers that they "didn't know what they would do without them." Other expressions of acknowledgement were described in the following:

- *"He always thanked people. At his funeral he left behind a message of thanks."* (AIDS informal male – Quebec)
- *"She never stopped thanking me and left me the most beautiful thing she had including my mother's wedding ring."* (cancer informal male – Quebec)
- *"She would touch me and show other signs of affection."* (cancer informal female – Quebec)
- *"He thanked me and called me his angel."* (cancer formal female – Nova Scotia)
- *"She gave me a blue-bird pin that was special to her. She would give me lots of hugs and kisses."* (cancer formal female – British Columbia).
- *"Yes, I would know through the squeezing of my hand."* (AIDS informal female – Nova Scotia)
- *"He couldn't express himself, but I saw in his eyes, his non-verbal language."* (cancer formal female – Quebec)

Caregivers of AIDS patients were significantly more likely than caregivers of cancer patients to indicate that their patients did not acknowledge their efforts, $\bar{n} = 6$; 16.7% versus $\bar{n} = 1$; <1%, respectively; $\chi^2 (1, N = 81) = 5.63, p < .05$.

Additionally, regional differences were uncovered. Caregivers in Nova Scotia ($\bar{n} = 29$, 100.0%) were more likely than caregivers in B.C. ($\bar{n} = 24$, 85.7%) and Quebec ($\bar{n} = 21$, 87.5%) to indicate that their caregiving efforts were acknowledged, $\chi^2 (2, N = 81) = 6.61, p < .05$.

A small number of caregivers reported that their patient was not able to physically acknowledge them in any way: *"It was not possible in the last month"* (cancer informal male – Quebec). Or that they had not received any form of acknowledgement even when a patient was able to do so: *"He stayed in absolute silence. He never thanked anyone"* (AIDS formal female – Quebec).

4. Religion and Spirituality

Sixty-two percent of all caregivers stated that religion and /or spirituality provided them with comfort and solace. Several noted the importance of prayer and meditation. They explained:

- *"I prayed a great deal because I felt I was running out of options."* (AIDS formal female – British Columbia)
- *"I am a Catholic believer and it helped me especially after her death because I was appalled by all the suffering and her death."* (cancer informal male – Quebec)
- *"I believed that he would be taken care of and live in a better life afterwards."* (AIDS informal male – Nova Scotia)
- *"Yes, I first asked why God was letting it happen. I continued to go to church to ask God for a peaceful death for my husband."* (cancer informal female – Nova Scotia)
- *"I pull in religion to help me and my patients"* (AIDS formal female – Quebec)

Among the answers given by caregivers who did not find such comfort include: *"No, I blamed God for what was going on,"* and *"I didn't feel the need."*

H. Caregivers' Final Thoughts

1. Positive Aspects of Caregiving

For more than half of all respondents, the most positive aspects of their caregiving work included being able to make a difference in a person's life, being able to provide support and comfort and help the patient along what they perceived to be a very difficult journey:

- *"Being able to help the person you love. I think it helped with the grieving process because I had done everything that I could do."* (cancer informal female – British Columbia)
- *"Satisfaction that I've done my best and provided emotional support."* (AIDS informal male – British Columbia)
- *"Knowing that I made a big difference in my mother's life."* (cancer informal female – Nova Scotia)
- *"Knowing that I made the last days for her as comfortable as could be."* (cancer informal male – Nova Scotia)
- *"Helping people go through a difficult journey. Being a guide to help people get through."* (cancer formal male – Quebec)
- *"Knowing that she made a difference to him and his family."* (AIDS formal female – Nova Scotia)

Others, (approximately one-fifth) reported that the most positive aspect was being able to help the patient die at home.

- *"Giving him his final gift – not having to hear the hospital buzzers and the patients moaning."* (cancer informal female – Quebec)
- *"Being able to let my father die in his own bed with all his affairs in order."* (cancer informal female – British Columbia)
- *"He got what he wanted. He had a beautiful home and he wanted to die there."* (cancer formal female – Nova Scotia)
- *"Knowing you have done something for someone, especially when they are deserted by their own family because of AIDS."* (AIDS informal female – British Columbia)

Approximately 10% talked about their contribution to a "good death." The majority of these were formal caregivers:

- *"It was a good death. Friends were around him, we bathed him. He was allowed to be exactly who he was."* (AIDS formal male – Nova Scotia)
- *"The actual end. I was able to make him and his family comfortable and they were appreciative."* (cancer formal female – Nova Scotia)

Some also mentioned that the comfort, support for family and in turn, the acknowledgement of the family were the most positive aspects:

- *"I helped him reach his family to let them know he was dying. He hadn't talked to his mother for over 8 years."* (AIDS informal female – Quebec)
- *"Thanks from the family and knowing you did a good job."* (cancer formal female – Nova Scotia)
- *"The patient's son. He showed/expressed recognition for my work. I felt this recognition came 'from the heart.'"* (cancer formal female – Quebec)

The remainder talked about bonding with the patient, having the opportunity to *"meet a very special person,"* helping with pain management, and having the strength to stay in control.

2. Difficult Aspects of Caregiving

For more than half of informal caregivers, watching the patient deteriorate and knowing they were going to die was the most difficult part of their experience. Their explanations included:

- *"Watching mother be extinguished. You don't get to process it because there is so much to do. You don't really get a minute to relate to things happening around you."* (cancer informal female – Nova Scotia)
- *"Knowing one day that he wouldn't be around. Kept wanting to put the day off – thinking that somehow he would survive longer."* (AIDS informal male – Nova Scotia)

- *"There is such a sense of helplessness. No matter what, you know the outcome. And there is nothing you can do about it."* (cancer informal female – Nova Scotia).

Several caregivers also mentioned the last few days or the very last day as being the hardest:

- *"The last few days were very difficult. It was a terrible strain. I realized he was getting worse."* (cancer informal female – Nova Scotia)
- *"Helping him prepare for it. When you are 29 you're not prepared to die. You are looking to live."* (AIDS informal female – Nova Scotia)

Related to this were informal caregivers seeing the patient in pain and trying to manage it throughout the last month of life.

- *"Pain management and the conversion period from morphine pill to injection. We couldn't get it quickly. We were left in the position to chase the pain. For example, we had to [give] the appropriate dosage ahead of the pain to beat it. I didn't know how much dosage to give, so she was experiencing pain"* (cancer informal male – British Columbia)
- *"Seeing her in pain. I felt bad that she had to undergo all the treatment she had to. It hurt me."* (cancer informal male – Quebec)

Informal caregivers also mentioned the challenges of dealing with certain difficult tasks:

- *"Bowel movements and cleaning up. I could only do so much."* (cancer informal male – Nova Scotia)
- *"Changing diapers. I felt it was hard for my mother. She had lost a bit of her dignity."* (cancer informal female – Quebec)
- *"Dealing with my friend's incontinence and the embarrassment. I tried to make him ok with it."* (AIDS informal male Nova Scotia)

In comparison, approximately one-third of formal caregivers found the actual process of death and dying the most difficult aspect of their experience caring for the patient:

- *"Sense of loss was difficult. There was an inability to resolve death – nothing gives us an answer and makes it okay."* (AIDS formal male – Nova Scotia)

- *"Last day when the breathing changed and he was close to the end. Knowing it wasn't going to be long before he passed away."* (cancer formal female – Nova Scotia)
- *"Anticipating the grief. I knew it was going to happen when he died."* (cancer formal female – Nova Scotia)

Another third of formal caregivers also reported difficulties with dealing with the family on a number of different levels:

- *"Not being able to tell his family [about his AIDS]."* (AIDS formal caregiver female – Quebec)
- *"Friends and family promise support – these are promises they may not keep."* (AIDS formal caregiver male – Nova Scotia)
- *"The informal caregiver's resistance to suggestions for changes in the way he carried out certain tasks and activities."* (cancer formal female – Quebec)
- *"Having the family to care because they are under so much emotional strain."* (cancer formal female – British Columbia)

For the remainder of informal caregivers, co-ordinating care, the intensity of care, providing the best care possible was the most difficult aspect of caregiving:

- *"I would have been tired if I had several palliative care patients at once. It would have been emotionally trying."* (AIDS formal female – Nova Scotia)
- *"Keeping track of what was going on with the patient – I would find out after the fact that patient had gone through some difficulties."* (AIDS formal male – Nova Scotia)
- *"There is such intense care needed. You never know what you would find when you were going to the patient's home."* (AIDS formal female – Quebec)

3. Done Differently

In reflecting back on their experiences, just over half of all caregivers reported that they would not do anything different. Here there was a marked difference between informal and formal caregivers. Almost twice as many informal caregivers were not satisfied completely with how they had cared for their family member or friend. Among these informal caregivers there were also gender differences. More than twice as many females vs. males responded that, in retrospect, they would have done something differently.

So although several reported that "they had tried their best" consistently, informal caregivers – the majority of them women – reported that they wished they had been more patient and understanding:

- *"Because of my exhaustion, I felt impatient and tried not to show it but I did."*
(AIDS informal female – British Columbia)
- *"I wouldn't have screamed at him."* (AIDS informal female – Nova Scotia)
- *"I would have controlled myself better. I 'lost it' with my dad a couple of times."*
(Cancer informal female – Nova Scotia)

Others stated that they would have asked for more help:

- *"I would have listened to the nurse about burn-out. I should have found more help. I should have found someone else for him and someone for myself to help me."*
(AIDS informal male – British Columbia)

Many regretted not spending enough time with the patient:

- *"I would have spent more time with him."* (AIDS informal male – British Columbia)
- *"I would have given more personal time rather than sticking him in front of the TV."* (AIDS informal female – Quebec)

And some wished they could have been more open about death with the patient:

- *"I knew very well the kind of cancer that she had and that she didn't stand a chance, but she didn't want to know, and I always gave her hope. When she realized she was going to die, she wasn't ready. Maybe I should have talked to her about it."* (cancer informal female – Quebec)
- *"I would have liked to have spoken with her about dying but she didn't want to."*
(cancer informal female – British Columbia)

One male AIDS informal caregiver in Nova Scotia regretted not having recorded a journal about the patient's process of dying. He explained: *"I would have recorded a journal of what it was like, pictures – anything to show people what it is like."*

I. Policy Recommendations

During the interview, caregivers were asked, *"In your opinion, what would make the palliative caregiving process more effective and/or more satisfying?"* According to the responses made by caregivers in B.C., Quebec and Nova Scotia, the following policy recommendations were derived.

1. The need to increase awareness of palliative care with the general public

- *"There is a need for a better understanding in society of the experience of palliative caregiving."*

- *"Palliative care is not well recognized. The public needs more knowledge about palliative care, especially now."*
- *"The public needs to understand that death is a normal thing – it happens to everyone."*
- *"We need consensus about what palliative care is about – what it means."*
- *"When I returned to work, people didn't understand. I was expected to be just as efficient. People are not aware of it. I felt weak and vulnerable."*

2. More education and training for both informal and formal caregivers

Given the increasing numbers of palliative care clients requesting care in their home, caregivers need to be educated better around a number of issues:

The process of dying and death:

- *"There is a need for training workshops for people to prepare for dying and how to care for the dying."*
- *"There needs to be better preparation of the family for end-of-life care."*
- *"Families are afraid in the hospital, let alone at home. Provide them with information."*
- *"Give lessons to people to prepare for death. It's an avenue of life and we don't know how to act when it is going to happen. We need training for the dying."*
- *"There needs to be better training for home caregivers. Often they are not educated enough about what they are doing. Many formal caregivers don't know what to do, how to react. They haven't got a clue."*

Illness trajectory (this concern was particularly reported by persons caring for HIV/AIDS patients):

- *"An AIDS caregiver (paid or unpaid) should know what to expect. They need to know about the disease, its symptoms and to know what happens over the course of the disease."*
- *"Home care workers should be more educated about working with people with AIDS."*
- *"We need more knowledge on 'how to care' for HIV, like take a course on it."*
- *"So many people don't know how to deal with AIDS patients, they need more training."*

The proper use of interventions, medications, medical equipment:

- *"There needs to be some kind of course for people who are doing palliative care (e.g., how to make a bed with a patient in it, how to move a person, how to administer medicine)."*
- *"There is a need for education to be better with medicines."*
- *"There is a need for more training in palliative medications."*
- *"There is a need for special teams, with specific expertise for home visits."*

3. Education of health care professionals

Respondents made clear that there is a need for more physicians and nurses trained in the art of palliative care.

- *"More education for physicians around death – they have to learn to deal with their fears – fear of failure when the patient dies, fear of getting a call regarding a death."*
- *"Sensitivity training for health practitioners. Very few are willing (to work) with people who have AIDS."*
- *"We need physicians trained in palliative care who are able to communicate effectively."*

4. Enhanced efforts to create an integrated multi-disciplinary team approach that will contribute to the continuity of care

Many respondents emphasized the need for consistency in who is caring for the patient to guard against a steady stream of strangers entering the home and providing care to the patient.

- *"We need to create a team where the same people are caring for the same person."*
- *"You need a whole system in place – you need a co-ordinated integrated team approach."*
- *"There needs to be more of a seamless system and structure."*

Some respondents also stated that the same quality of care that is available in a hospital setting should be available at home:

- *"We should provide the kind of complete team and resources in the home that are provided in the hospital."*

5. Better communication between health professionals, families, and patients

- *"Medical professionals need to be more honest with their patients"*
- *"Honesty with family and patient about what's going on and preparing them for the journey."*
- *"What was...lacking was a doctor that could support us and talk to us. If someone had met with us to explain the process, give us information, it would have been enough."*

6. To ensure a patient's choice and right to end-of-life care, allocate more health care resources into the community

- *"We need to have a plan – a program where everything is covered whether the family has money or not."*
- *"Government should be putting more money into the program."*
- *"For those who want to die at home, we need the resources available to support the family because acute care is hugely expensive."*
- *"Right now, we are restricted to what palliative care we can offer because of decreased money."*
- *"People who do not have the financial means should not be required to assume such heavy expenses."*
- *"The major problem for me was the financial aspect. I am the sole supporter and have no income and had not been prepared for this."*

7. Increased support for caregivers

In general, there was a consensus that more needs to be done for the caregivers' physical and mental wellbeing. As one AIDS formal caregiver summarized effectively *"More support equals an increased ability to cope which equals a more positive death."* Other points include:

Counselling and other outreach supports:

- *"Counsellors to work with people who are caregivers"*
- *"Palliative care is physically and emotionally draining. It requires more than one person to do this job."*
- *"We need to have someone to call and talk about the person and the experience."*
- *"24 hour support."*

Respite:

- *"More respite needed for families."*
- *"Government must realize that it is a demanding process and that death at home requires 24 hours of time."*

Support and bereavement groups:

- *"We need support groups in the community."*
- *"There is a need for us to get closure."*
- *"I need more support to help me with my process. Someone to talk to ... at the end."*

And as one male respondent stated:

- *"There are lots of supports for women, but very few bereavement groups for men."*

Many respondents also emphasized the need to have such support readily available, because caregivers often do not have the time, ability, or resources to search out such assistance.

- *"There is a need for immediate support that comes to the caregiver rather than the caregiver having to find out or hunt for it. An overall planner would be very helpful."*

Respect and recognition:

- *"Unpaid caregivers should never be pushed aside."*
- *"More understanding of the specific needs of informal caregivers in rural areas."*

8. Given the large volume of support provided by family/friend caregivers, compensation for their care in forms of stipends or increased tax breaks may be employed

- *"Some way to give some sort of salary to caregivers in a form of a direct payment."*
- *"There should be funding for palliative care – for people who want to be with a friend/loved one during the last month of life. People should have the option for paid leave from work to stay at home with a dying friend/relative."*
- *"There should be some kind of compensation, like minimum wage given to the family."*

- *"Consideration should be given for the time invested either in the form of pay or of a 'special leave' in order to allow willing family members to stay at home and to be with those they love."*

9. As with other home care services, palliative care should be culturally sensitive and responsive to the diversity of cultural beliefs of death and dying

- "The palliative care we are delivering is western society's palliative care. We should embrace new and different ethnic groups. For instance, palliative care is different for each culture and therefore there would be different practices. Some ethnic groups see death very differently and yet palliative care is not culturally sensitive."

V. Conclusions

This study of palliative home caregivers in three provinces has revealed a great deal of information about the impact of giving such care on caregivers, their families and the patient's families. Indirectly, it also affords us a view of the collateral and residual effects of providing palliative care in the home. The impacts range from economic to social and psychological and include many items and aspects not typically measured in economic costing studies. The long-term impacts of providing such care are not covered in this study, and would be a fruitful subject for future investigations in this area.

This study is based on the self-reports of caregivers, recollected after the death of the patient and transmitted to an interviewer. These data concern the primary care provider, and do not take into account directly the experiences of the other members of the caregiving team, whether formal or informal caregivers. Similarly, these data are not about the patient, and make no attempt to judge how the patient may have experienced the care they received. The majority of the patients in the study were identified as Caucasian or White (80%). Further investigation into the diversity issues presented by palliative care patients and their caregivers is warranted to more fully understand and directly identify possible differences between groups.

While three regions of the country were studied, the three sites were in some ways different. In particular, the Nova Scotia sample had more rural influences compared to the B.C. and Quebec samples, the latter two being pulled entirely from Vancouver and Montreal. Halifax, Vancouver and Montreal are differently sized urban centres. However, there are many regions of Canada not included in this study, making cross-national generalizations from these data difficult to identify.

Having said this, these data reveal some interesting results and indicators of the situations facing both formal and informal caregivers providing palliative care in the home. Perhaps not surprisingly, a key element of the findings relates to the benefits, not the costs, of providing palliative home care. For both formal and informal caregivers, male and female caregivers valued the opportunity to make a difference and provide support to a person by assisting them with dying at home. Similarly, the caregivers overwhelmingly reported that providing palliative home care gave meaning to their lives, and that their relationship with their patient had improved throughout the process. In addition, most of the caregivers reported that their efforts were acknowledged by the patient.

The caregivers did not provide care without support. Many parties, including family and friends, social agencies, employers and others supported the individual caregivers. Clearly, even in the context of having no national home care system, and no national standards for providing home-based palliative care, it seems that many individual Canadians and their social networks are rising to the task of assisting patients and family members in dying at home.

The largest differences between the respondents are between the formal and informal caregivers, as would be expected between a group of employees and a group of unpaid voluntary carers. In addition, the unpaid group usually had strong emotional

links to the person and to the outcome of the dying process. Therefore, these differences in standpoint explain a variety of differences between economic impacts (e.g., out-of-pocket expenses) and psychological impacts that were revealed in the study. In general, the informal caregivers spent three times longer providing care to the patient than did the formal caregivers. Informal caregivers spent significantly more time providing emotional support and engaged in a wider variety of tasks than did the formal caregivers.

In addition, the formal caregivers were less likely to think that they might have done something differently in the caregiving process. Conversely, the informal caregivers were twice as likely to be unsatisfied with how they had cared for their family member or friend. Perhaps because of their emotional links, the informal caregivers also had to deal with guilt and regret. They often had fewer boundaries to limit their caregiving time, so they experienced burnout and exhaustion that affected their performance.

Twice as many female informal caregivers than males experienced this regret and wished that they had done things differently. These retrospective wishes included changing their ability to ask for help, stay in control, spend time with the patient and be more open about death with the patient. This is possibly reflective of the amount of responsibility for emotional caregiving that women may take in relationships and family life.

Otherwise, the gender differences were less strong than the differences between formal and informal caregiving status. Among the formal caregivers, there was no difference in the nature of the caregiving tasks performed. In general, however, both male and female caregivers reported equal rates of emotional hardship as a result of providing palliative home care in the last month of life. This time period may be so fraught for caregivers, either formal or informal, or male or female, that experiencing emotional impact is inevitable. It may be that studying gender differences for a long caregiving period, including non-palliative situations would reveal gender differences of a different ilk.

This study reveals some differences in the nature of the tasks that were taken up by women and men, and some differences in the nature of the support services utilized by women and men. However, sex and gender were less predictive than formal/informal status in defining the experience of the last four weeks of life. Having said that, it is interesting to note that more female informal caregivers (than male) reported that providing care had an impact on their family life. In a diagnosis-related result, female informal cancer care providers reported more physical impact than their male counterparts. These gendered effects likely reflect gender roles and sex-based physical differences respectively.

Male caregivers were more likely to report out-of-pocket expenses. Informal caregivers reported more of these expenses than the formal caregivers. Interestingly, though, these patterns did not correspond with reports of economic hardship. The gap between spending money and interpreting it as hardship is likely mitigated by how much income a person controls to begin with, and whether or not the caregiver feels that the money could have had other more important uses.

Finally, regional differences emerged in patterns that likely reflect local policy and program availabilities. Given the lack of a national set of standards and programs, it is not surprising that the services used are incomparable across regions. In addition, geographical influences in the three study sites may have had an effect on determining some of the services used by the caregivers and their patients.

Perhaps the most revealing data emerge from the recommendations made by the caregivers regarding the provision of programs and policies in support of palliative home caregiving. Both formal and informal caregivers called for more training and education regarding palliative care issues, including the process of dying, the trajectory of illnesses, and pain management and other interventions. Caregivers also called for a more streamlined team of caregivers, mixing formal and informal, and different kinds of services to provide seamlessness and better communications with all concerned.

Finally, the caregivers called for more resources and planning to be devoted to palliative care in Canada, which would even out the availability of services across regions and income groups. The caregivers called for some efforts to compensate unpaid caregivers through compensation or tax schemes to recognize and facilitate their involvement in palliative caregiving for their family and friends².

In summary, the calls of national organizations for this crucial, final form of home care to be more regulated and organized are supported by the caregivers interviewed in this study. Taking account of the thoughts, experiences and recommendations of these caregivers will undoubtedly decrease the magnitude of the final payments and increase the benefits associated with providing palliative home caregiving in the last month of life.

² On June 3, 2002, the Government of British Columbia, Ministry of Health Services, announced a new policy that permits payment to some family members who provide caregiver services (Government of British Columbia, 2002).

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